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National Strategy for the Integration of Persons with Disabilities

Report ■ National Consultation on Continuing Care Needs in First Nation Communities

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National Strategy for the Integration of Persons with Disabilities

Report ■ National Consultation on Continuing Care Needs in First Nation Communities

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Health Canada

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Executive Summary

Five issues were identified during the National consultation process; jurisdiction, funding, service delivery, program utilization, access to rehabilitation services, training and liability.

Provincial and territorial governments have developed comprehensive, full-service continuing care programs but, because of the position taken by provincial and territorial governments that on-reserve services are a federal responsibility, territorial and provincial continuing care services are not generally extended to First Nation communities. This is increasing the pressure on First Nation communities as provinces move towards deinstitutionalization, early hospital discharge and community-based care.

These issues of jurisdiction and authority continue to limit the quality and scope of on-reserve continuing care services and to restrict severely the opportunities for future development in this area.

All regions identified under-funding as a serious problem for the existing, limited on-reserve continuing services. This was supported by data showing the average provincial expenditures for the provision of continuing care services in the sample of First Nation communities was much lower than in the non-Aboriginal sample.

In particular, under the current funding regime, there is little coordinated case management or functional integration of continuing care resources with other health and social services in the community. There was widespread concern across all regions that even the minimal resources provided at the present time were not being used efficiently or effectively.

With higher rates of morbidity across all age groups, First Nations tend to have higher relative percentages of their home care case-loads in the 15- to 64-year-old age group and less in the 65-year and older group. In the Manitoba study, for example, approximately 51% of all home care clients were younger than 65 years of age. The British Columbia First Nation Summit found that 54% of its sample were under the age of 60 years.

The utilization pattern found that First Nation communities receive less home care services than non-Aboriginal communities. This was particularly true for personal care services, home nursing care and rehabilitation or support services such as physiotherapy and respiratory therapy, which are generally not available on-reserve.

It was also found that non-Aboriginal communities had access to a much broader array of health professionals such as doctors, physiotherapists, dieticians, occupational therapists and others to deliver health care services. Only seven "other health professionals" were identified as working in this area within the First Nation communities, compared to 22 in the non-Aboriginal sample.

The consultation process also found that Band health or social service workers who determine client eligibility and allocate services have had little if any training in client assessment or case planning and management.

The lack of appropriate training places the health and safety of First Nation clients at risk as well as exposing the providers of in-home services to potential liability. In the Ontario region, it was noted that homemakers have

difficulty providing personal care services due to a lack of training. Homemakers in the Yukon region identified the need for more training in the area of personal care skills such as the proper way to handle clients with mobility problems.

The lack of on-reserve home nursing services was found to be a critical issue which impacted on both the quality of services to First Nations clients and the liability of service providers.

The Steering Committee proposed five recommendations to address the issues identified during the consultation process. These include: Health Canada to secure a mandate for home care nursing; the establishment of a comprehensive/integrated community continuing care program, under the responsibility of one federal department; the development of case managed funding options which will recognize regional diversity; and, resources for training and development programs to support the availability of qualified health providers.

Introduction

As part of the 1991 National Strategy for the Integration of Persons with Disabilities, Medical Services Branch, Health Canada, was allocated resources for consultation with First Nations on the health component of on-reserve and Inuit continuing care needs over a period of three years.

A multipartite (First Nations/Inuit/DIAND/MSB) Steering Committee, with representation from the Assembly of First Nations Health Commission, the National Aboriginal Network on Disability, the National Indian and Inuit Community Health Representatives Organization, the Labrador Inuit Health Commission, Department of Indian Affairs and Northern Development (DIAND) and Medical Services Branch (MSB) Headquarters, regional and field staff, was established to manage the MSB activities under the Disabilities initiative.

Regional consultation with First Nations took place in 1992/93. Objectives and guidelines for the consultation process were developed by the Steering Committee and reviewed and approved by a regional Working Group, which implemented the consultation at the regional level.

The regional consultation process was planned and implemented jointly with First Nations and DIAND. The process involved obtaining information from four to eight status First Nation communities and Labrador Inuit and Innu communities, and an equivalent number of non-Aboriginal communities, matched in terms of their degree of remoteness and isolation, for each MSB region across the country. When completed, the regional submissions provided comparable information on federal and provincial continuing care programs, such as funding formulas, eligibility criteria, training, and the availability and utilization of homemaking, personal care and home nursing services.

Information on three in-home components of continuing care – homemaker, personal care, and home nursing services – was collected as part of the consultation. The provincial and territorial governments provide these three components as a comprehensive and integrated part of their continuing care programs; Medical Services Branch, Health Canada has neither the mandate nor the resources to provide home nursing care. DIAND does provide homemaking and personal care services through the on-reserve Adult Care program. Due of the interdependency of continuing care programs, it was decided that all three components must be part of the consultation process in order to accurately reflect the in-home continuing care needs in the selected First Nation communities.

For the purpose of the consultation, the following definition of community continuing care was developed:

> Continuing care is a system of service delivery encompassing a range of insured, extended and uninsured health and social services for all age groups, addressing the holistic health, social and personal care needs of individuals who do not have, or have lost, some capacity for self-care. These integrated services are designed to improve individual functioning, and provide culturally appropriate support and care in the community, where possible.

Aboriginal peoples experience conditions that result in a lower quality of life compared to other Canadians, ie. lack of access to health and social services and educational resources; material and economic deprivation; poor diet; inadequate housing and sanitary facilities; alcohol and tobacco abuse; family instability; and low self-esteem deriving from unemployment, violence and stigmatized minority status.

Approximately 40% of the Aboriginal population is under the age of fifteen. This is comparable to the Canada of 50 to 100 years ago, and has important implications for the planning and delivery of health and social services in First Nation communities.

The 1991 Aboriginal Peoples Survey (APS) found the rate of disability among Aboriginal people to be more than double the rate of non-Aboriginal Canadians, with Aboriginals living on-reserves and settlements reporting the highest disability rate, 33%; the Inuit reported the lowest rate, 29%. For the 15 to 34 age group, living on-reserve, the disability rate was 22.4%, compared to 7.9% for the Canadian population. In the 35 to 54 age group, the Canadian population disability rate was 13.7%, while the Aboriginal on-reserve rate was 35.5%. In the 55 and older group, the disability rate was 70.1% on-reserve, compared to 52.8% for Canada's total population. These morbidity rates are a strong indicator of the need for community continuing care services. Morbidity encompasses the causes of poor health, but more importantly, the impact that these conditions have on the physical, social and mental functioning of the individual.

Figures in this report reflect actual data for the on-reserve communities surveyed. It should also be noted that, for the purpose of this report, the survey group is First Nation people on-reserve. Because MSB also funds services for the Inuit of Labrador, data has also been included on this population group. Statistics reported have been gathered by health or social services workers on-reserve. The APS figures are based on self-identification of both Aboriginal status and disability.

The adult Aboriginal population will approximately double in the next 23 years. The fastest growing segment will be the 45 to 65 age group; a 185.3% increase will occur between 1988 and 2011. The highest rate of growth for the elderly (65+), will be found in Alberta, British Columbia and Saskatchewan. Growth in the Aboriginal population is due to increases in life expectancy, and the reinstatement of individuals as Aboriginal under the provisions of Bill C-31.

MSB statistics indicate that First Nation peoples living on-reserve are hospitalized at two to three times the rate of the non-Aboriginal population, and that hospitalization rates of First Nation peoples 20 to 44 years of age are three times that of the non-Aboriginal population, often because of a lack of continuing care services in the community.

The Report has been divided into three sections. The first, Regional Summaries, provides comparable information on funding formulas, eligibility criteria, training, and the availability and utilization of homemaking, personal care and home nursing services, as well as service gaps on a regional basis. The second section, Consultation Analysis, examines issues raised during the consultation, including: jurisdiction, funding, service delivery, program demand, access to rehabilitation services, and training and liability. The final section, Directions, offers approaches for continuing care program development in First Nations, and includes recommendations to address the full spectrum of community-based home care needs on-reserve.

Atlantic Regional Summary Report

Introduction

Information was collected from the four Atlantic provinces to contribute to a report outlining MSB activities under the Consultation for the National Strategy for the Integration of Persons with Disabilities.

The report presents data on continuing care from four First Nations or communities and four non-Aboriginal communities concerning service demand and availability, funding formulas and eligibility criteria for homemaking, personal care and home nursing services. Information on training is also provided and current gaps in services are highlighted.

The Atlantic Region consists of the four provinces of New Brunswick, Nova Scotia, Newfoundland and Prince Edward Island. As separate provinces, conditions, services, systems and structures are quite different in each place. Within the region, there are also various First Nation groups who have distinct cultures, as well as unique historical, social, political and environmental perspectives.

A contact person in each community was interviewed in to collect information on continuing care needs and services. In most cases, this contact was the community health nurse. In all communities, at least one other person was contacted either in person or by telephone to provide supplementary data.

New Brunswick

In New Brunswick, the Provincial Department of Health and Social Services is in a period of transition as it reorganizes on a regional basis.

The information that follows is based on interviews in the First Nation community of Big Cove and the rural community of Richibucto, two communities of roughly the same size and approximately the same distance from major centres of New Brunswick.

As indicated in Table 1, there are substantial differences in the provision of continuing care services between First Nations and non-Aboriginal communities in New Brunswick.

Although the communities have approximately the same populations, the non-Aboriginal community is integrated within a comprehensive regional health care delivery structure. The First Nation community, however, is very much on its own. This means that in the non-Aboriginal community, clients fit into a system that is organized to provide the same quality of care to all New Brunswickers. Any service that is needed by an individual can be provided through health provider teams at the county level, and those services are supervised and supported by staff and resources at the regional and provincial levels.

In the First Nation community of Big Cove, services are primarily provided by those who can be hired to work on the reserve. There is not a large population base through which resources can be shared; services are therefore quite limited.

The elderly are treated differently as well. In non-Aboriginal communities, seniors' residences, special care homes and other institutional services are the norm. In First Nation communities, however, off-reserve institutional care is most often not culturally

Table 1
Continuing Care Summary Data, New Brunswick

Community Name/Type	Big Cove Aboriginal Non-Isolated	Richibuctou Non-Aboriginal Non-Isolated
Population	2300	1700
Number of chronic/disabled	0-19 yrs: 56 20-64 yrs: 110 65 yrs+: 35	0-19 yrs Unknown 20-64 yrs " 65 yrs+ "
Number of people requiring services	0-19 yrs: 1 20-64 yrs: 34 65 yrs+: 20	0-19 yrs: 4 + 20-64 yrs: 15 + 65 yrs+: 26 +
Number of hours required Cost of services	Adult care: $28.25 per day; on call 24 hrs/day 7 days/wk. Homemakers: $5.00 per hour; 15 hrs/wk/client.	Homemakers: $7.50-$9.50 per hour – 10.5 hours per week. Home Nursing: $30.00 per hour – varies.
Description of services available		
Homemaker services	Services available with adult care and homemakers programs.	Services available from Red Cross and La Havre.
Personal care services	Services available with adult care and homemakers programs.	Services available from Red Cross.
Home nursing	Regular service by CHNs and CHRs – 1 client seen by extramural hospital.	Services available from extramural hospital and a range of other health professionals.
Eligibility criteria to access services	Referrals by doctors and CHN. Final decision by CHN, juggling needs and resources.	Based on clients needs as assessed by multidisciplinary team.
Who is responsible for client assessment?	Community health nurse.	Team of health professionals.
Is there a funding formula?	Unknown	Varies.
Training	No formal training for homemakers and personal care workers.	Homemakers/Personal Care: formal six-week training program.

appropriate. The provision of home-based and community-based services, therefore, are more critical.

Key contact persons emphasised the communication difficulties and cultural isolation that is experienced by First Nation communities. According to Community Health Nurses in the First Nation communities, information from provincial health programs is not shared with the reserves. This makes the referral process difficult, time consuming and expensive.

Table 2
Number of Clients Receiving Continuing Care in Big Cove

Age: 0 – 19	Age: 20 – 64	Age: 65 +	Total
Homemaker: 2 ACP – 1 HMP – 1	Homemaker: 22 ACP – 18 HMP – 4	Homemaker: 17 ACP – 14 HCP – 3	41
Personal care: 0 ACP – 0 HMP – 0	Personal care: 8 ACP – 4 HMP – 4	Personal care: 2 ACP – 1 HMP – 1	10
Health care: 0	Health care: 0	Health care: 0	0
Total 2	**Total 30**	**Total 19**	**51**

ACP: Adult Care Program
HMP: Homemakers Program
Note: Some individuals are clients of more than one service. Numbers were not collected for nursing services supplied by CHN, CHR. These clients are usually served by one of the other two programs and the nurses try to teach these care givers to deliver most nursing services.

There also appeared to be a difference in morale for health workers in the communities. Excitement and enthusiasm was expressed by workers in the non-Aboriginal setting about the challenge and enjoyment of their jobs, the good relations with doctors and other members of their interdisciplinary teams, and about the feeling that they were on the leading edge of coordinated regionally based home health services. In the First Nation communities, frustrations were expressed about relationships with doctors off-reserve and there were different opinions about the priorities for service development.

In the First Nation community of Big Cove, a total of 248 people with chronic health conditions or disabilities were identified. This includes 47 children who are asthmatics. Of the total, 17% are 65 years of age or older and 58% are between 20 and 64 years of age.

As of February 1994, a total of fifty-one people require continuing care services in Big Cove First Nation. Fifty, or 91% of these require homemaking services and the remainder require personal care. Health staff identified continuing care needs for individuals requiring homemaker and personal care services for post-operative care, chronic conditions and conditions of frailty due to old age. Some disabled Band members, who require home care health providers, cited examples where the physically disabled were forced to move off-reserve to get the care they needed.

Information on continuing care needs in the non-Aboriginal community of Richibuctou were gathered from the Extramural Hospital manager and coordinator, supervisor, special needs programs, single entry point coordinator, and the public health nurse. Home care by Extramural Hospital staff is considered acute care, but it has been included here because it is delivered in the home to people who would otherwise be institutionalized. Special needs (disabled) adults and children are included, as are the frail elderly.

Table 3
Continuing Care Clients in Richibuctou

Age: 0 - 19	Age: 20 - 64	Age: 65 +
Homemaker: 3 + RC – ? LH – 3 LH – 5	Homemaker: 6 + RC – 1 + LH – 0	Homemaker: ? RC – ? LH – ?
Personal care: 0 LH – 0 RC – ?	Personal care: 1 + RC – 1 + LH – 0	Personal care: 8 + RC – 8 + LH – ?
Health care: 1	Health care: 8	Health care: 18
Total 4 +	**Total 15 +**	**Total 26 +**

RC: Red Cross
LH: La Havre
Note: Red Cross provides service to some other individuals, but these numbers were not obtained. The symbol "+" means there are a few more over the number given.

Table 3 shows the number of individuals in Richibuctou who are currently receiving continuing care services from all the various agencies involved in the area. Unfortunately, it was not possible to determine the number of chronic/disabled in the area. However, since each agency stated that it does not have any waiting lists at this time, it can be assumed that the number receiving services equals the number requiring services. Staff of the Extramural Hospital, for example, stated that they have the personnel to handle their case load of approximately 100 patients.

Services

Three main programs have been developed in the Big Cove First Nation to provide continuing care services. The Adult Care Program (ACP) provides support to families and individuals who require continuing care. The client (usually an elderly person) nominates someone (usually a family member) to assist with housekeeping, shopping, hobbies and other activities. For some clients (5 of 38), personal care is also provided under the Homemakers Program.

The Adult Care Program workers are paid $28.25 per day. Funding is provided by DIAND and administered by the Band Council through its Social Development Department.

The Homemakers Program provides both housekeeping and personal care services to individuals on the reserve who require continuing care. This care is provided to chronic care and disabled patients in all age groups and is also available to post-operative clients. The service is often used as respite care by families that have a chronic care or disabled relative living with them. Currently, six women are employed by the program to serve 13 clients. Five of these clients require personal care services.

The units of service are based on client need. There is a minimum of four hours a week and a maximum of 20 hours a week. The current average is 15 hours per week per client. The homemakers are paid $200 – $275 per week. Funding is provided by DIAND and administered by the Band Council through its Child and Family Services Agency.

There are no formal home nursing services in Big Cove. The community health nurses and the community health representatives sometimes make home visits to acute or chronically ill patients, but this is primarily on an ad hoc basis. Their major responsibilities are in health education, health promotion and running specific clinics.

The Extramural Hospital currently serves one patient on-reserve. This is a provincially funded program costing approximately $30 per hour. Medi Gas, a private firm, provides oxygen therapy (provision of supplies and some education six times a year) to three or four patients on-reserve.

A wide range of continuing care services is available in the non-Aboriginal community of Richibuctou:

- *Extramural Hospital*. The Extramural Hospital (EMH) is an innovative homecare program providing a range of acute and palliative care services to a case load equivalent to that of a 200-bed hospital. Services include: nursing, intravenous medication, physiotherapy, nutritional counselling, respiratory care, oxygen therapy, sick room equipment and others. The EMH also coordinates the provision of home care services. On average, a nurse with the EMH will see 5.3 clients per day. Care to individual patients varies. A visit may last from 15 minutes to 2 hours. The frequency of visits may vary from twice a day to once a month.

  Costs for the EMH range from $18 to $75 a visit. The average is $30 per hourly visit. Services are covered by provincial health insurance.

- The *Single Entry Point* (SEP) Program is available to clients over 65 years of age. Clients receive extended services in their home up to a value of $770 a month, based on an assessment by a social worker and a nurse. This may include any of a variety of services, including meals-on-wheels, homemakers, and EMH services. Heavier care (up to a value of $1470 a month) can be provided if recommended by a 'Panel', and if the family is willing to care for the patient and/or pay some of the costs. Care over and above this level usually requires admission to a nursing home.

- *Community-based services for disabled children and adults*. These developmental, rehabilitative and preventive services are provided to physically or mentally disabled children (0-19) and adults (20-64) to avoid institutional care. Various services include: homemaker services to family, relief and respite care, sitting, counselling and psychological services, residential services (foster home type arrangement), vocational services and financing of medical equipment.

- The Community-based service average is 10.5 hours per week. An individual service plan (ISP) is developed for each case based on criteria concerning age, condition, family support system, parents' income and an assessment by a health professional (ie. neurologist, speech pathologist).

- *Red Cross Programs* (Homemakers, Meals-on-Wheels, etc.). Trained employees provide housekeeping and some personal care services. Although there is currently no meals-on-wheels program in Richibuctou, there is one in the nearby communities of Buctouche and St-Louis-de-Kent.

- Employees in the homemakers program are paid $9.50 per hour. The Red Cross is contracted by the provincial government to provide services to individuals in need. The cost of the meals-on-wheels program is usually shared between the recipient and the

EMH program (if the service was requested by EMH) or one of the social service programs.

- *La Havre Program.* This program provides housekeeping services, personal care and sitters to those in need. Ten and a half hours a week, per client are provided. The cost of the service is $7.50 per hour.

Eligibility/Referral

In Big Cove First Nation, the community health nurse makes the final determination on the time units and type of care required for each client. There are standard referral forms in use which outline the reason for referral, recommended type of care, duration and frequency of care. These referrals are reviewed at least once each year. On occasion, the community health representative or social development administrator may recommend an individual for a particular service, but the community health nurse will make the final decision.

At times, a doctor may make a direct recommendation for a certain service for a patient under his/her care (often following discharge from hospital). In most cases, however, these recommendations are also channelled through the community health nurse.

Clients need to travel 15 to 30 kilometres from Big Cove to visit a doctor. If they need to be referred for things such as X-Rays or physiotherapy, they would be referred to Ste. Anne Hospital, 30 kilometres away). The X-Ray department is busy and is only open part-time. There is often a six-week waiting list to see the physiotherapist. To see a specialist, patients travel to Moncton, Halifax or Fredericton. The referral process is often quite drawn out and frustrating.

In Richibuctou, clients are admitted to the EMH by a doctor who orders services based on the patient's condition. A team, including a nurse and social worker, evaluate the case and determine the details of how and when these services will be provided, based on resources available and what care can be taught to family members. If the services required are extensive (over a certain value per month), a panel consisting of nurse, doctor, social worker, EMH manager, and possibly other health professionals directly related to the case, will make a final decision of how care will be provided, both short and long term. Although there is no formula for determining services, consistency is maintained because the same group of people draw on their professional experience to review each case.

Referrals are made within Kent County by the first service provider contacted by the client (this may have to be confirmed by a doctor). Special needs children are referred to an agency by the Extramural Hospital. Frail elderly persons requiring some nursing care are referred to the Extramural Hospital by social workers.

Training/Supervision

There are no formal training or certification requirements for the continuing care workers at Big Cove First Nation. Adult Care Program workers may have attended a basic first aid course and received some one-on-one training from the Community Health Nurse (CHN) or Community Health Representative (CHR), if requested.

Homemakers at Big Cove usually have some first aid and CPR, but this is not a requirement. Any training they receive is usually acquired on-the-job on an ad hoc basis from the CHN or CHR. This training may include dressing changes, post-operative care, and home

dialysis. In 1982, some of the current homemaker staff attended a six-week Red Cross Homemaker Training Program and then a short refresher course in 1991. The Homemakers Program is administered and coordinated by a staff member who does some supervision of other employees.

In the non-Aboriginal provincial system, the Red Cross provides six-week training courses for employees of their homemakers program, for which they award a certificate. This training includes practical experience at a nursing home and periodic refresher courses and supervision by Red Cross staff. EMH staff may also be involved on a monthly basis with a client who is receiving homemaker services to monitor certain conditions and therefore provide ad hoc supervision and support to homemaker staff. EMH staff felt that the training of their homemaker staff is sufficient. Human Resources Development Canada (HRDC) provided funding for these training programs in the past.

La Havre Program has just instituted a six-week training course modelled on the Red Cross Program. Most of their current employees have not had any training.

There is no special training required for special care home workers – other than being over 18, having first aid training and having a yearly medical exam.

Service Gaps at Big Cove First Nation

- A meals-on-wheels program is needed.
- Many of the current homemakers require training.
- Homemakers are overworked and underpaid. Community health nurses reported that they "have to beg homemakers not to quit," because they are tired and there are not enough of them. Others want to work, but there is no money to hire them. Better working conditions are required.
- The substantial amount of money currently being spent on medical transportation could be used to fund an on-reserve physician to provide for both continuing care and acute care needs.
- While the Extramural Program provides some service on-reserve, there should be more cooperation between off-reserve and on-reserve health services.
- Appropriate services for the disabled such as respite/relief services and appropriate housing are not available on-reserve.

Nova Scotia

In Nova Scotia, the *Blueprint Committee for Health Care Reform* released a report in April, 1994 which recommended that the province be divided into four regions, each with its own board receiving an annual budget from the provincial health department for running hospitals and planning and funding services. Community boards would apply to regional boards for funds to run primary health care or home-based services.

The information that follows is based on interviews with staff at Millbrook First Nation and the rural non-Aboriginal community of Stewiacke. These communities are comparable in size and in their distance from major cities.

Table 4
Continuing Care Summary Data, Nova Scotia

Community Name/Type	Millbrook Aboriginal Non-Isolated	Stewiacke Non-Aboriginal Non-Isolated
Population	900	1200
Number of chronic / disabled	0-19 yrs: 4 20-64 yrs: 40 65 yrs+: 6	0-19 yrs: 0 20-64 yrs: 2 65 yrs+: 32
Number of people requiring services	0-19 yrs: 4 20-64 yrs: 40 65 yrs+: 6	0-19 yrs: 0 20-64 yrs: 2 65 yrs+: 32
Number of hours required Cost of services	Varies depending on needs; staff are available 7 days per week, if needed. Homemaker and personal care: 10 hrs per week	One hour a week per client for nursing care
Description of Services Available		
Homemaker services	Services available	Services available
Personal care services	Services available	Services available
Home nursing	Services available from CHN, CHR and VON under contract	Services available
Eligibility criteria to access services	Must have a referral letter from a doctor, based on medical condition.	Based on coordinated home care program criteria (age, condition, family situation)
Who is responsible for client assessment?	The doctor and occasionally the nurse.	Home care assessor
Is there a funding formula?	MSB/DIAND to band council	Province/Municipal/ Community Homemaker and Personal care costs by individuals Nursing care by province.
Training	RNs have formal training. CHR specialist course at university. Homemakers have no formal training	

The home care needs in Millbrook First Nation are often simply for friendly, social contact. The extended family seems to ensure that nutritional needs are met, but people often get lonely. In the non-Aboriginal community, however, the greatest need for the elderly seems to be nutritional because some clients are not regularly supported by family members and they find it difficult to care for themselves on their own.

MillBrook First Nation functions independently, outside of any larger system of government or program delivery. There is a team of three providers who like working together, are known and respected in the community, and seem to be meeting current continuing care needs.

In the non-Aboriginal community of Stewiacke, however, the provision of services is less coordinated, with several different people involved along the way. There is a real absence of a team approach. There was frustration expressed about the number of people that can be involved with a case at one time. The nurse felt it would be more cost and time-efficient for them to be responsible for their own assessments.

In both communities, there was talk about the need for a greater range of continuing care services. In Millbrook First Nation, people expressed the belief that some of these needs could be met by better training of adult care providers, while in the non-Aboriginal community, seniors' day care, better discharge care (such as physiotherapy) and a volunteer program were proposed.

Millbrook is a Mi'kmaq community located approximately 100 kilometres from Halifax. It has a population of 477, with the majority of people between 20 to 64 years of age. Continuing care services are provided by Band-employed personnel such as the community health nurse, community health representative and adult care coordinator, with occasional input from VON services.

In Millbrook, the frail elderly make up the majority of continuing care clients and require regular home care support. Their needs are related to chronic conditions such as diabetes, hypertension, heart conditions, arthritis and asthma. Needs are also related to surgical complications, cancer, senility and loneliness, and social isolation. There are two paraplegic clients.

Continuing care needs in Millbrook are for homemaking services, personal care, patient education, friendly contact, nursing care and training of family members involved in care. There is a need for more funding for home care and personal care services in order to support the traditional Mi'kmaq practice of helping people stay in their homes with their families.

There are currently 50 persons with chronic conditions and disabilities in Millbrook First Nation. Eighty percent of these are between the ages of 20 and 64 years. Only 12% are 65 years or older. Continuing care services are currently being provided to 54 clients (some clients receive more than one service).

In Stewiacke, continuing care services are provided by the coordinated Home Care Program under the provincial Department of Health. Services generally include home nursing, homemaker services, housing, and volunteer services. There are currently 34 people with chronic conditions or disabilities, all of whom are receiving home care services. All of these clients receive home nursing care and ten receive homemaking and personal care services. The majority of continuing care patients (94%) in Stewiacke are 65 years of

age or older. Disabilities were secondary to other conditions of the elderly, i.e. cerebrovascular accident, diabetes, cancer, blindness, arthritis, peripheral vascular disease, immobility, loneliness and poor nutrition. There were two people with multiple sclerosis who required personal care services.

Services

Three main programs have been developed in Millbrook First Nation to provide continuing care services:

- The community health nurse provides general nursing care to individuals who require continuing care support. The client is usually an elderly person who is seen in the home on their own or with a family member. The community health nurse offers a wide range of services including nursing care (ie. medical administration, dressing changes, vitals checked, patient education, emotional support, patient advocacy, counselling, and making funding applications for adaptive equipment). The community health nurse is fluent in Mi'kmaq and therefore has an excellent rapport with the elders.
- The community health representative provides patient advocacy and support and has regular contact with Band members with health problems and needs. Other roles include securing funding and obtaining adaptive aids and equipment.
- The adult care coordinator is employed part-time by the Band Council to coordinate the homemaker and personal care service. She performs these duties as part of another position with the Band Council. She hires and supervises homemakers who provide a variety of services such as meal preparation, grocery shopping, house cleaning, personal care, and respite care. There is a great range of services provided, as they attempt to meet most of the clients' identified needs. The maximum time available is ten hours per week per client. This can happen over a two day period, as long as the worker is available and agreeable. The client and worker decide together on the hours. The Band Council receives funding from DIAND for this service. Homemakers receive $5 per hour, with no benefits, or insurable weeks for unemployment.
- The Victorian Order of Nurses (VON) provides general nursing care services and is available when the need arises, for example, when the community health nurse is not available. A referral to the VON is required from the attending physician. The community health nurse usually works closely with the VON in assessment and follow-up.
- Continuing care clients requiring rehabilitative services go to the Truro/ Colchester Hospital or to a private facility. MSB pays for this service but requires a referral letter from the doctor stating the condition, need, and time units required for treatment. The cost is approximately $42 per hour.

Under the provincial Continuing Home Care Program, the following services are available to clients in the non-Aboriginal community of Stewiacke:

- Home care nurses provide nursing care and medication administration in the client's home but also provide patient counselling and emotional support, such as bereavement counselling and supporting the spouse of an ill person. They also act as patient advocates and provide information on where to get various supplies and equipment.
- There is a full time Certified Nursing Assistant available to provide care when needed, day or night, and a part-time registered nurse providing approximately

nine hours of continuing care services (CCS) to clients weekly. Clients receive approximately one hour of care per week, although not everyone is seen every week.

- Homemakers provide personal care, meal preparation, basic housekeeping, laundry, respite for family caregivers, child care, parenting skills, and some handyman services. CCS clients can receive up to 28 hours of service per week and up to four hours of respite care per week. The average received, however, (based on assessed need) is eleven hours per month.
- Homemakers are paid $5 an hour. Funding is from the Department of Health, with allocates the money to a community agency responsible for the administration of the program. In Stewiacke, the agency is Children's Aid and Family Services of Colchester County. Funding is available to clients, depending on regular monthly income. User fees are charged.
- An In-Home Support Service Program, providing weekly and evening respite care, is also available through the local municipality.
- People who require other services, such as physiotherapy, must go to Truro or Halifax. However, accessibility to these services is poor since there is a waiting list and post-operative surgical patients take priority.

Eligibility/Referral

To receive continuing care services in Millbrook First Nation, an individual must obtain a referral from a doctor. The referral letter must be specific about patient condition, the type of care required, and the required time units. Nursing and health care providers will then do their assessments. Often the health care providers will have the final say in determining whether someone is eligible for services.

In the provincial system, requests for services in non-Aboriginal communities such as Stewiacke are made directly to the Coordinator of the Home Care Program. A Home Care Assessor visits the home to do an initial assessment and to determine if a client is eligible, what his or her needs are, and who will provide the care. Referrals can be made by physicians, clients themselves, family or community members. Reassessments are usually carried out every six months.

To be eligible for home care, clients must be either 65 years of age or older, disabled or be from a family at risk and require assistance in remaining independent.

Training/Supervision

Adult care workers have no formal training requirements and are not required to have any license or certificate. There is no formalized mechanism for recruitment, selection or orientation. Workers are hired when there is a need in the community. The Adult Care Coordinator (ACC) often hires on the recommendation of the client receiving the care and will encourage clients to hire a family member.

Homemakers are usually oriented to their roles by the client. At times, the ACC, community health nurse or community health representative will provide on-the-job training. Some workers on their own initiative will take a training course such as St. John's Ambulance or training related to their client's condition (for example, how to give insulin, how to apply certain dressings). The homemakers are informally supervised by the ACC with the assistance of the community health nurse and community health representative.

In Stewiacke, homemakers are hired by the agency which receives the provincial funding. They may or may not have prior training.

Once hired, there is a mandatory 400-hour, 13-module training program which includes body mechanics, adult protection and medical conditioning. Homemakers are supervised by the Regional Home Care Coordinator.

Service Gaps in Millbrook First Nation

- More funding for homemaker and personal care services is required to hire more workers.
- Improved salaries, training and supervision is required for on-reserve home care workers. The Adult Care Coordinator stated that it is difficult to recruit and retrain workers for any length of time and that there is minimal job satisfaction as a result of the lack of training.
- Improved access is required to equipment and mobility assistance devices (such as bath tubs, rails and ramps). Funding is also required for home renovations for the disabled.
- Improved transportation is required for continuing care clients.
- Improved access to disability pensions is needed. Disability pensions are now integrated with social assistance and this has caused some confusion for those living on-reserve, where social assistance is provided through DIAND.

Prince Edward Island

In Prince Edward Island, continuing care services are generally provided by the Home Based Program under the Department of Health and Social Services. There are five regional offices with a Multidisciplinary Team covering designated catchment areas.

Data was collected from the communities of Lennox Island First Nation and Tyne Valley (non-Aboriginal). The communities have roughly the same population and are approximately the same distance from the cities of Summerside and Charlottetown.

In First Nations, however, demands were made for programs to deal with more fundamental issues such as the high rate of illiteracy and the need for culturally sensitive home and personal care workers.

Both communities are receiving services that are appropriate to their needs, but those needs were very different. In Lennox Island First Nation, most clients are in the 20 to 64-year range and require primarily mental health services. In Tyne Valley, the client population is the elderly, who require home nursing and homemaker services because of their conditions.

Both communities have the same access to provincial government services, according to those interviewed, but First Nation people often do not access the services that are available to them because "of a long-standing distrust of social service personnel" and an unwillingness to accept culturally inappropriate non-Aboriginal services.

Lennox Island, a First Nation of 465 people (300 on-reserve), is separated from the mainland by a causeway. Approximately 60% of the population is under 40 years of age. There is a high rate of unemployment, illiteracy and social problems such as adolescent conflict, poor parenting skills, substance abuse, depression and family violence.

Table 5
Continuing Care Summary Data, Prince Edward Island

Community Name/Type	Lennox Island Aboriginal Non-Isolated	Tyne Valley Non-Aboriginal Non-Isolated
Population	300	250
Number of chronic / disabled	0-19 yrs: 12 20-64 yrs: 33 65 yrs+: 4	0-19 yrs: 2 20-64 yrs: 15 65 yrs+: 6
Number of people requiring services	0-19 yrs: 12 20-64 yrs: 33 65 yrs+: 4	0-19 yrs: 2 20-64 yrs: 15 65 yrs+: 6
Number of hours required cost of services	Varies, depending on clients needs	Homemakers: 2.5 hrs/week Home Nursing: 5 hrs/week
Description of services available		
Homemaker services	Services available but not utilized due to distrust.	Services available.
Personal care services	Services available but not utilized due to distrust.	Services available.
Home nursing	Home nursing provides a variety of services, including extensive mental health counselling.	Includes Multidisciplinary Regional Team (ie. OT, Nursing, Community Support Worker)
Eligibility criteria to access services	As assessed by doctor and Community Health Nurse. Further assessments by other health professionals, if necessary.	Residence requirement. Must be assessed as needing service.
Who is responsible for client assessment?	As above.	Team does assessment and case management.
Is there a funding Formula?	Unknown.	Provincial and Federal EHCS. User fees (sliding scale) for homemaker services.
Training	Recognized formal training for nurses. No formal training for other workers.	Recognized formal training for team. Homemakers: ten-week program.

Community care services are provided for the most part by a Band-employed community health nurse, with occasional referral to the O'Leary Regional Multidisciplinary Team under the provincial Department of Health.

There are 49 persons with chronic conditions and disabilities in Lennox Island First Nation, two-thirds of whom are between the ages of 20 and 64 years of age. Currently, all 49 are receiving some nursing services from the community health nurse. Four of these people are also seeing a mental health worker from the province. Approximately ten people require homemaking services, but do not utilize them.

The community health nurse stated that approximately 75% of her continuing care caseload consisted of clients with counselling and emotional support needs. These needs were related to issues of substance abuse, family violence, history of sexual abuse, parenting challenges, adolescent behavioural problems, childhood learning disabilities, and illiteracy. A part-time mental health worker funded by the province (1/2 day per month) has been hired to deal with some of this caseload. The community health nurse felt this was helpful, but still inadequate given the extent of the needs of this area.

There are two clients with chronic schizophrenia who require considerable community-based support and crisis intervention (including medication administration, follow-up and emotional support), to avoid lengthy hospitalizations.

Other continuing care needs were related to conditions of the aged: osteoporosis, arthritis, diabetes, immobility, and patient education.

The village of Tyne Valley has a population of approximately 250 people, although the surrounding area encompasses a larger population of approximately 400 people. Continuing care services are provided by the Regional Multidisciplinary Team which offers assessment and case management to continuing care clients. The regional team is part of the overall Home Based Program under the Prince Edward Island Department of Health and Social Services. There are currently 23 people with chronic conditions or disabilities receiving services in Tyne Valley. Of theses, two are under 20 years of age, 15 are between 20 and 64 years of age and six are over 65 years of age. Three clients are receiving homemaker services, 15 receive home care nursing and five people are being seen by an occupational therapist. At the present time, no clients are receiving personal care services.

Services

The community health nurse provides a wide variety of continuing care services to the community including counselling, personal care, patient education, medication administration/ follow-up, client assessment, dressing changes, diabetic blood checks, vitals, crisis intervention with psychiatric patients, coordination with mental health workers, recommendations to Band Council, non-insured health benefits administration and record keeping, and acquiring adaptive equipment.

The community health nurse works 40 hours per week. She covers two evenings a week, but no weekends. The community health nurse stated that she had approximately 15 hours per week to see continuing care clients or 30 minutes per client per week.

Homecare and personal care workers are currently available to clients through referral to the provincial Multidisciplinary Regional Team. However, as mentioned earlier, this is not being done.

A mental health worker visits a half day per week and provides counselling to four people. The nurse refers people she feels need special attention. The worker spends 45 minutes per month per client. The funding for the mental health worker is provided by the province.

Occupational therapy services are available by referral to the regional team. However, coverage is not guaranteed because of a large caseload. As a result, the community health nurse often consults by telephone with the occupational therapist regarding her clients. A physician, funded by the province, visits the First Nation two times per week.

Residents of the non-Aboriginal community of Tyne Valley receive services of the provincial Home Based Program including nursing, homemaking, occupational therapy, physiotherapy, community support services and adult protection. The team will occasionally take on other members, for example a minister, as the need arises. The following are the main services being utilized by the Tyne Valley clients:

- Nursing services include dressing changes, foot care, personal care, patient education, administration of medication, physical assessment, friendly visits, and consultation with the team. The average time spent with each client is approximately one day per week per client. The nurse tends to see most people in the hospital during a foot care clinic, and also visits people at home for assessment and treatment.
- Homemakers provide a variety of services related to home management, i.e. meal preparation, house cleaning, laundry, and shopping. They may also do some personal care such as bathing and grooming. Approximately five half-hour sessions per client per week are provided. The maximum is five four-hour sessions per week. The homemaker, along with the occupational therapist, will assess and make final recommendations for services. There is also a minor user fee based on a sliding scale.
- Occupational therapy provides services such as assessment for adaptive equipment and education regarding their use, rehabilitative assistance to improve functioning, counselling, and consultation regarding accessibility programs for developmentally delayed children. An average of 1/2 hour per client per month is provided.
- A Seniors' Day Program, funded by volunteers with support from the hospital, also meets many continuing care needs. It operates from the hospital and offers social activities, exercises, guest lectures and therapeutic baths.

Eligibility/Referral

Continuing care clients at Lennox Island First Nation are assessed by the physician, who visits twice a week, or by the community health nurse. Referrals are made to the physician and community health nurse by the individuals themselves, family, or community members (i.e. employment counsellor or teachers). Follow-up is based on regular clinic/home visits. Clients must be Band members and must reside in Lennox Island.

For homemaking or other health care services such as occupational therapy, the community health nurse makes a referral to the regional team which conducts its own initial

assessment using the Department of Health's eligibility criteria. The regional team then compiles a case plan based on assessed needs. This is done in close collaboration with the community health nurse. Clients travel to Summerside for long-term rehabilitation or acute psychiatric treatment.

In Tyne Valley, individuals must be referred to the regional team by a physician, another team member, rehabilitation staff, friends, family, or the individuals themselves. There is no single entry point to the system, although there are attempts to develop a system similar to the one in New Brunswick. Appropriate members of the team carry out home assessments and develop treatment programs and follow-up care.

The eligibility criteria includes residence in PEI and being assessed as needing at least one of the following services – home care nursing, occupational therapy, homemaking, community support, adult protection, and physiotherapy.

Training/Supervision

Lennox Island does not employ homemakers or personal care workers. Provincially employed homemakers take a ten-week Residential Care Program funded by the province.

All provincial team members are responsible to the team and collaborate on many cases. There is a lot of information sharing and team learning from their regular liaison meetings. Team members reported feeling very positive with the team concept.

Service Gaps at Lennox Island First Nation

- More health staff are required to provide more continuity of care, i.e. community health representatives for patient advocacy, friendly contact and other services.
- A full-time mental health worker is required to deal with the high number of psycho-social problems.
- Culturally sensitive homemakers/personal care workers or band employed workers are needed to provide continuing care services.
- Teachers aides for one-on-one attention for children with learning difficulties are required.
- Programs are required to deal with the high rate of illiteracy.
- A substance abuse counsellor is required.

Newfoundland

The Newfoundland Continuing Care Program is designed to provide coordinated comprehensive home care services to persons in convalescent, rehabilitative or chronic stages of illness, or for persons with functional disabilities; to coordinate existing service within geographical boundaries of the program; and to support persons and families who wish to have services provided in the community.

The program provides homemaking services, personal care (up to three hours per day), physiotherapy, occupational therapy, laboratory services, social work, medical supplies and nursing services. To be eligible, clients must be in the convalescent, rehabilitative, chronic or terminal stage of illness or have functional disability, and must be assessed as requiring professional treatment and/or personal care services in order to be able to

return to or remain at home without risk, and have a physician willing to provide medical care.

The St. John's Newfoundland Home Care Program provided the following information on its expenditures for the fiscal year 1992-93:

A. Amount of each dollar spent per category of expenditure

Administration	17%
Client assessment and coordination	12%
Direct client service	71%

B. Amount of each direct client service dollar spent per service:

Homemaking	51%
Nursing	40%
Rehabilitation	6%
Laboratory	3%
Social Work	0%

C. Average costs:

Cost per client	$1,092.00
Cost per client day	$16.00

Table 6 provides an overview of continuing care statistics and community populations of Conne River First Nation and its matched non-Aboriginal community of St. Albans.

Services

The Conne River Medical Clinic provides full continuing care services in the areas of homemaking, personal care services and home nursing. Health services have been transferred to the Band and the medical clinic offers a comprehensive range of treatment, community health and home care programs. At the present time, the Band employs six home health aides who have been trained and certified by the Victorian Order of Nurses as well as three other untrained aides who each work with one client.

The community health nurse and the social worker determine the time units and type of care required by home care clients. The Band uses a formal written formula to assess clients' needs. The average cost of homemaking services is $10 per hour. Home health aides are supervised by the community health nurse and social worker.

Table 6
Continuing Care Statistics
Conne River First Nation and St. Albans

Community	Total population	# and % chronics/ disabled	Number requiring services	Hrs/Wk provided	Cost per hour
Conne River First Nation	700	78 11.1%	HM 1 HM/PC 4	HM 10 PC 133 HC 0	$10
St. Albans (Newfoundland)	1586	Unknown	HM/PC 9 HC 26	HM/PC 714 HC *	N.A.

***Note:** Three Acute Care clients receive one or two nursing visits a week (all visits are about thirty minutes). Nine Chronic Care clients receive visits every two weeks. Nine Chronic Care clients receive visits once a month. Five Continuing Care clients receive visits ranging from once every six weeks to once every six months.

In the non-Aboriginal community of St. Albans, nine clients are receiving a combined homemaking/personal care service. The majority of these require 24-hour care. The provincial Enriched Needs Program provides, on average, approximately 11 hours of paid help daily, seven days a week. The remainder is provided by family members. An additional 26 clients are receiving home nursing care.

To be eligible for the Enriched Needs Program, clients must have a medically documented disability and have an assessed need for supportive care. The program is based on financial eligibility, once need is established. Assessments are completed by the Gander and District Continuing Care Program through a contractual arrangement with the provincial Department of Social Services.

In St. Albans, referrals for home nursing services are accepted from any health provider, hospital, or any individual or group in the community. Assessments are then carried out by the nursing coordinator to determine if services will be provided and what form they will take.

Training/Supervision

At Conne River Band, there are six home health aides trained and certified by the Victorian Order of Nurses. The Band uses the guideline of one trained personal care worker for approximately 100 people. The Community College in Newfoundland (Grand Falls) provides a diploma course.

The province does not offer training for homemakers or personal care workers. For some nursing, the nurses must hold a B.Sc. in community health prior to being hired. For homemakers in St. Albans, there is a ten-week course provided by the Community Unity program, which is funded by the Department of Human Resources Development and the province. There are a number of untrained workers providing homemaking and personal care services.

Atlantic Regional Issues

The following major issues were identified for the Atlantic Region:

- Basic housekeeping and homemaker services may be more available on-reserve than off-reserve.
- Personal care services, home nursing and specialist services are more available in non-Aboriginal communities. The quality of care is also superior because of highly trained staff.
- Homemaker and personal care workers have higher levels of training in the non-Aboriginal communities.
- Salaries, benefits and conditions of service for homemaker and personal care workers are higher in the non-Aboriginal communities.
- In both Aboriginal and non-Aboriginal communities, there is a need for ongoing counselling to meet psychosocial needs. This need is especially prevalent in First Nation communities.
- Respondents indicated that most required services are being provided at the present time. However, these services are provided in different ways in each group of communities.
- In the First Nation communities, the community health nurse, community health representative, homemakers, adult care workers and others attempt to provide the care that is needed. They may not have the skills or training that is needed, but in most cases they attempt to learn from each other and provide what they can. They realize

most clients prefer receiving services on-reserve because of the lack of understanding (in most cases) when accessing services off-reserve.

- In the non-Aboriginal communities, a full range of continuing care is available. It is just a matter of assessing a client's specific need and arranging for delivery of the appropriate service. Even in very small communities, it is very easy to integrate into the larger health care structure and receive the needed specialist care.
- In the future, as the First Nations population increases and ages, it will not be possible to meet the necessary continuing care needs with present resources. It will not be possible to establish new services unless new resources are provided. The situation is much different in non-Aboriginal communities, where all needed services are in place and individuals with needs can be accommodated within existing services.
- In some cases, provincially funded services are available to First Nation people, but they usually do not access these services because they are not aware of them; because they do not trust the care providers; or because the services are culturally inappropriate for First Nation people.
- Examples were given of disabled people who were forced to move off-reserve to get the care they needed. The care was not available on-reserve and provincial services would not come on-reserve to provide it.
- For long-term institutionalized care, it is necessary for First Nations and (in some cases) non-Aboriginal people to move from their own communities. However, non-Aboriginal clients would be able to move to an environment that is culturally and linguistically familiar. Most First Nation people have no desire to access such services because they view them as foreign and alienating.
- First Nations often have difficulty matching services to needs because of the different funding arrangements for various programs and services.

Labrador Inuit and Innu Summary Report

Information was collected for four coastal Labrador communities, Nain, an Inuit community, the Innu community of Sheshatshui and two non-Aboriginal communities, Cartwright and Forteau.

Through the Canada/Newfoundland/Native Peoples of Labrador Health Agreement, Health Canada provides a contribution to the Province of Newfoundland in respect of Newfoundland's expenditures on public health nursing and the operation of nursing stations in the two Innu and five Inuit communities. Grenfell Regional Health Services (GRHS), a provincial health organization, delivers insured health services to residents of Labrador. In addition, Health Canada provides funding to the Labrador Inuit Health Commission and the Innu Health Commission for non-insured health benefits, community health services and addictions programs.

Labrador Inuit

There are approximately 5,500 Inuit people living in the Labrador coastal communities of Nain, Hopedale, Makkovik, Postville, Rigolet and in the Upper Lake Melville communities of Northwest River and Happy Valley/Goose Bay.

The Labrador Inuit Health Commission is directly funded by Health Canada to provide some health services to the coastal communities and the Upper Lake Melville area. The Upper Lake Melville area, with a population of about 10,000, includes about 2,000 Inuit and is the main administration and service centre for the North Coast communities. Services such as medical care, social services, and transportation for the disabled are more readily available. The Lake Melville Association of Disabled Adults helps to facilitate independent living of its members.

The population of Nain is young and there is a relatively small proportion of elderly that may require services. Furthermore, because of the presence of large extended families, and the current critical housing shortage, few elderly people actually live alone. The following home health care needs were identified in these communities:

- Housing adequacy is a major concern for the disabled. Many homes lack running water, proper heating, and (where required) wheelchair ramps.
- Appropriate public transportation for the disabled is also a concern. In Postville, for example, there are no provisions for assisted transportation to the airstrip for medically related trips. Furthermore, coastal boats serving the community are not equipped for embarking, disembarking or transporting wheelchair passengers. The community school lacks wheelchair accessible washrooms.
- There are many cases of learning disability due to alcohol abuse. There are serious concerns that children with mental disabilities are not receiving proper attention at school.
- Major health problems in the area include arthritis and chronic lung disorders. In Makkovik, for example, there are nine children with severe asthma and a number of adults with chronic lung disorders. However, the Grenfell Regional Health Services, administered by the provincial government and responsible for health services in this area, does not have a respiratory specialist. People with severe

arthritis, some of whom need mobility devices, have severe problems because houses have no running water and need firewood for heat.

- There are no homemakers at present in the coastal Inuit communities. Some untrained home support workers were provided using the Employment Assistance Program but this arrangement proved to be unsatisfactory.
- There is no formal schedule to assess needs and allocate services. At the moment, accessibility to services is based on an "as needed" basis, when funding is available.
- Because of the lack of home care services, people who require support are moved to institutions outside of their home communities. Language and cultural differences make this move extremely stressful for elderly Inuit people.
- In the coastal communities, there are virtually no long-term facilities or extended care programs. Accessibility to services such as physiotherapy and occupational therapy is almost non-existent.

Labrador Innu

The Innu are Naskapi-Montagnais non-Status Aboriginal. The 1,300 Innu are concentrated in the two communities of Sheshatshui and Davis Inlet. Health services are provided by the province through Grenfell Regional Health Services. The Innu also receive some funding for community health services and non-insured health benefits from Health Canada.

In the Innu community of Sheshatshui, respite and personal care services are being provided through a temporary employment opportunities program. Grenfell Regional Health Services provides the services of a home care nurse who visits some clients once or twice a week. Client assessments are done by Grenfell Regional Health Services. At the present time, there is no training for respite workers.

In the non-Aboriginal community of Forteau, continuing care services are provided by the Labrador South Home Care Inc. Services include personal care services, homemaker services, meal services, family counselling and

Table 7
Population And Selected Continuing Care Statistics, Innu Community And Matched Non-Aboriginal Communities

Community	Sheshatshui (Innu)	Cartwright (Non-Abor.)	Forteau (Non-Abor.)
Population	1,000	635	2,200
# Clients Requiring Services	0-19 yrs 3 20-64 yrs 5 65 yrs+ 4	0-19 yrs 0 20-64 yrs 0 65 yrs+ 0	0-19 yrs 3 20-64 yrs 14 65 yrs+ 53
# of Hours Required	N/A	0	1,000 hrs.

teaching services, supportive care services, respite care services and other related services. Client assessments are performed by the home care coordinator, social worker, and nursing staff. Staff training is provided by St. John's Ambulance, the Department of Health, Public Health, internal staff and volunteer groups.

In the non-Aboriginal community of Cartwright, up to fifteen hours of emergency home care is available to patients. This is referred to as "hands-on-care", which can include a range of services from homemaking, personal care or home nursing. Client assessments are carried out by GRHS public health staff. There is no charge for emergency home care and it is not based on financial need. Homemakers are hired as needed. Over the last year, three temporary homemakers were hired for limited periods. Eligibility criteria are established by the provincial Department of Social Services and the GRHS. On-the-job staff training is provided by GRHS home care services and by the public health nurse. Personal care attendants do not require or have pre-service training.

Training

To create a pool of trained homemakers who could be employed if funding became available, the Labrador Inuit Health Commission conducted a training program for home support workers in 1988. Three people completed the course. To date, however, funding for such workers has not been available.

Service Gaps

The assessment report on the conditions surrounding the Labrador Inuit and Innu with disabilities recommended the following:

- All homes of Labrador Inuit and Innu who are physically challenged should possess running water, have acceptable standards of construction to ensure proper heating and safety, and be modified to suit the needs of the disabled;
- Basic home care programs need to be established, including both medical health care and non-medical basic human need assistance;
- Community roads, transportation facilities and community buildings need to be upgraded to facilitate movement of the physically disabled;
- More resources are necessary to deal with mentally challenged children in the schools. Teachers need special needs training;
- There is also a need for community education on various health issues to help prevent chronic conditions such as arthritis and lung disorders;
- Support groups are needed to empower the disabled to improve their situation and to increase awareness of and access to programs and services for the disabled.

Québec Regional Summary Report

Introduction

In the Québec region, the consultation on home care services was completed by Aboriginal Consulting Services. Surveys were completed in eight First Nations and eight non-Aboriginal communities using three questionnaires which examined available home care services in the community, provided a profile of clients, and described the training of home care staff. The Federation of Local Community Service Centre (Centres locaux de services communautaires – CLSC) was asked to identify the CLSCs that could be appropriately matched with the First Nation communities.

Since the CLSCs serve a number of communities within a municipality, it was not always feasible to use population size as the major criterion for matching communities. The decision was made to use location as the deciding factor in most cases.

In Québec, there are 157 CLSCs providing home-based services, intensive home-based services, and long-term residential care. In 1984, to improve consistency and improve referrals to the proper services, Québec adopted a regional admission coordination system based on a single assessment tool for establishing patients' functional independence and medical status.

Québec's provincial Home-based Services Program includes the following service components:

- Regular home care services (services provided for fewer than five hours per week) such as assistance with basic personal care, food, mobility and transfers, housekeeping, sitting, domestic help and assistance with meals; nursing care; and, in some CLSCs, rehabilitation, occupational and physiotherapy, social and medical services; follow-up and assessment; and advocacy.
- Intensive home care services (over five hours a week) such as those above, but provided for 15 to 18 hours of service a day, seven days a week.
- Home help for the disabled such as direct personal care (in particular, physical help and non-specialized nursing care) and domestic help. An average of 15 hours a week is allowed.
- Specialized home care services for people with chronic respiratory problems and terminal kidney failure.
- Day centres and Day hospitals.
- Temporary accommodation.
- Community-based programs, including activities such as friendly visits, companions, meals-on-wheels, advocacy, group meals and self-help meetings.

With respect to the on-reserve home care system, the report noted the following:

> "In the past few years, general maintenance and personal care services covered by contribution agreements with Indian and Northern Affairs have come under the direct supervision of the social service programs of First Nation communities. However, home support health services have not been taken over to the same extent and are often almost non-existent or dependent on the intervention of neighbouring CLSCs." (P. 1)

Service Demand

Tables 1 to 3 provide an overview of some characteristics of clients of home care services in the Québec region. Table 1 demonstrates that, on a per capita basis, there are more clients receiving home care services in the First Nation communities sampled than in the non-Aboriginal communities. When interpreting this table, however, it is important to note that morbidity among First Nations is two or three times the national rate.

Table 2 shows that the majority of clients in the First Nation sample (64.7%) are over the age of 65. Approximately 18.5% were between the ages of 56 and 65.

Table 1
Percent Clients (All Home Care Support Services) (Clients/total population)

First Nation communities:	Range 2.2% to 14.6% per community Average = 4.93%
Non-Aboriginal communities:	Range 1.2% to 4.2% per community Average = 2.46%

Table 2
Clients By Age Group – First Nation Communities (n = 438)

Age group	Number of clients	Percent of total
10 or less	8	1.8
11 - 20	4	1.0
21 - 55	62	14.2
56 - 65	80	18.3
66 - 75	128	29.4
76 - 84	102	23.4
85 plus	52	11.9

Note: The non-Aboriginal communities used different age groupings, making a comparison of the two groups impossible.

Table 3
Clients by service category

	First Nation		Non-Aboriginal*	
Service category	**#**	**%**	**#**	**%**
Homemaking	257	58.7	567	33.5
Personal care	85	19.4	568	33.5
Health care	313	71.5	1320	78.0
Total clients	**438**		**1693**	

***Note:** Only four communities reporting.

Table 3 shows that a higher proportion of clients in First Nations receive homemaking services than in non-Aboriginal communities. However, the reverse is true with respect to personal care and health care services. The utilization rate for these services is greater in non-Aboriginal communities than in First Nation communities.

The average hourly cost of home care services was much lower in First Nation communities, particularly for homemaking and personal care services (Table 4). The costs for nursing services were similar in both groups of communities.

Table 4
Average hourly cost
Home care services, Québec Region

Component	First Nation Communities	Non-Aboriginal Communities
Homemaking	$7.35	$16.27
Personal care	$9.58	$20.86
Health care services (Nursing care)	$25.29	$27.03

Table 5
Homemaking services by type,
First Nation and Non-Aboriginal Communities

	Number of communities providing the service	
Task	**First Nation communities**	**Non-Aboriginal communities**
Vacuuming	7	8
Floor cleaning	8	7
Clean appliances	8	6
Dish washing	8	8
Meal planning/prep.	7	8
Laundry	8	8
Clean bathroom	8	7
"Meals on Wheels"	2	4
Sub-Total	**56**	**56**
Cleaning yard	4	1
Carrying firewood	4	1

Availability of Continuing Care Services

Table 5 suggests that basic homemaker services, such as cleaning and meal preparation, are equally available in both First Nation and non-Aboriginal communities. One difference is that Meals-on-Wheels is only available in two or 25% of the First Nation communities, compared to one-half of the non-Aboriginal communities.

The services of cleaning the yard and carrying firewood were not included in the totals since these tasks would be more likely to be done in reserve communities than urban communities, where many clients live in apartments and/or do not require firewood.

A slightly higher percentage of non-Aboriginal communities reported providing their clients with personal care services than their First Nation counterparts (Table 6).

Table 6
Personal care services by type,
First Nation and Non-Aboriginal communities

	Number of communities providing the service	
Task	**First Nation communities**	**Non-Aboriginal communities**
Bathing	7	8
Hair washing	6	8
Feeding assistance	6	4
Getting in/out of bed	5	7
Dressing	7	7
Total	**31**	**34**

Table 7
Health care services by type,
First Nation and Non-Aboriginal communities

	Number of communities providing the service	
Task	**First Nation communities**	**Non-Aboriginal communities**
Nursing services	7	8
Occupational therapy	2	3
Physiotherapy	2	5
Foot care	3	0
Respiratory therapy	4	4
Sub-total	**18**	**20**

Table 7 illustrates that about 10% more non-Aboriginal communities than First Nation communities reported providing the health care services listed to their membership. However, the Québec report notes a critical point that was identified in the discussions with the First Nation communities included in the consultation:

> "The (home care) services provided do not always reflect actual needs, especially for home support health care services, which are not a specific part of the community health services program in First Nation communities. No planning or program has ever brought home support health care services to the fore and, consequently, they have been neglected." (P. 9)

However, this table significantly understates the reality of health care services in First Nation communities. As stated in the Québec regional report (p. 33):

> "It clearly emerges...that a larger number of health services are covered in non-Aboriginal communities than First Nation communities, except for the community of Kahnawake. As an example, only the communities of Manawan and Kahnawake indicate that they provide occupational therapy and physiotherapy services, whereas these same services are provided by six and eight CLSCs respectively."

More detailed information on this issue is provided in the next section.

Program Staff

For homemaking services, all First Nation and non-Aboriginal communities had a homemaker or familial auxiliary to provide the above services. In the First Nation sample, one community indicated that it also uses a nursing assistant; two communities use nurses and two communities use community health representatives to deliver these services.

Both groups of communities used similar staff resources for personal care services.

However, in the First Nation communities, approximately 72% of homemakers and familial auxiliaries were employed on a part-time basis. The equivalent figure for the non-Aboriginal sample is difficult to summarize because one community reported volunteers as part-time workers. However, the corresponding percentage of part-time workers in the non-Aboriginal communities would probably be in the 30 to 40% range.

For health care services, six First Nation communities utilized nurses, compared to seven non-Aboriginal communities. In four First Nation communities, community health representatives were also used to provide health care services.

The non-Aboriginal communities had access to a much broader range of health professionals to deliver health care services, such as doctors, physiotherapists, dieticians, ergotherapists and others. Only seven "other health professionals" were identified as working in this area within the First Nation communities, compared to 22 for the non-Aboriginal communities.

Without including physicians, the number of "other health professionals and technicians" involved in home support care (other than homemakers, familial auxiliaries, nurses, and

community health representatives) in both groups of sample communities were as follows:

First Nation Communities: 5

(Four at Kahnawake – one full-time and one part-time occupational therapist; one full-time and one part-time physiotherapist; and one at Mashteuiatsh – part-time foot care)

Non-Aboriginal Communities: 18

(including occupational therapists, physiotherapists, ergotherapists, respiratory technicians, and rehabilitation technicians)

Existence of a Formula or Protocol to Determine Service Eligibility

While the vast majority of non-Aboriginal communities used a formula or protocol to determine service eligibility, only half of the First Nation communities had a similar formula (see Table 8).

Training

Four of the communities in the First Nation sample indicated that their homemakers or familial auxiliaries had taken a training program. However, all homemakers in the eight non-Aboriginal communities have taken basic training programs such as the familial auxiliary or beneficiary care courses. In addition, the familial auxiliaries in six out of the eight non-Aboriginal communities have taken further specialized training such as a security displacement course, nutrition course, care course, continuous education, foot care, palliative care and gerontology.

Only two First Nation communities – Maniwaki and Kahnawake – provided special on-the-job training programs. These programs were usually funded by HRDC and were provided for homemakers and community health representatives. However, six out of the eight non-Aboriginal communities indicated that they had provided special on-the-job training opportunities for a number of their staff, including familial auxiliaries, nursing assistants and nurses. Most of these were funded by the CLSCs themselves and provided by professionals working for the CLSC or through contractual arrangements with universities or other groups. CLSCs were able to draw on their substantial internal technical resources to further the training of their staff.

Service Gaps

Table 9 provides an estimate of personal care services and nursing services which are non-existent or poorly covered in both First Nation and non-Aboriginal communities. One-half of the First Nation communities surveyed reported that their nursing services were inadequate. Furthermore, First Nation communities identified over three times as many personal care services which were non-existent or inadequate in their communities as did their non-Aboriginal counterparts.

First Nations were more likely than their non-Aboriginal counterparts to identify all of the factors listed in Table 10, especially "budget", "lack of trained personnel" and "lack of financial resources" as the major reasons for their service gaps.

Although the survey questionnaire included a question designed to capture an estimate of the gap between current services and actual needs, only one First Nation community – Wendake – answered this question. They estimated that

Table 8
Number of First Nation and Non-Aboriginal communities with established formulae for home care services

	# of First Nation communities	# of Non-Aboriginal communities
Homemaking services	5 (63%)	8 (100%)
Personal care	4 (50%)	8 (100%)
Health care services	3 (38%)	6 (75%)

Table 9
Personal care and nursing services not covered or poorly covered in First Nation and Non-Aboriginal communities

	First Nation communities	Non-Aboriginal communities
Personal care	10	3
Nursing care	4	0

Table 10
Causes of lack of service coverage (All home care services)

Component	First Nation communities	Non-Aboriginal communities
Lack of trained personnel	6	5
Services offered for less than a year	2	0
Services under authority of external organization	2	2
Insufficient number of service hours	5	3
Other causes	16	8
	(budget = 11)	(budget = 4)

an additional 33 people require home maintenance services (a 62% increase over the current caseload); an additional 69 people require personal care services (a 345% increase); and an additional 116 people require health care services, an increase of 109%.

Ontario Regional Summary Report

Introduction

The Ontario regional report was undertaken by the Nishnawbe-Aski Nation through a contribution agreement with Medical Services Branch (MSB) of Health Canada. Ten First Nation and six non-Aboriginal communities across Ontario region were surveyed, based on the minimum data requirements requested by MSB. In the First Nation communities, questionnaires were completed by welfare administrators, community health representatives, community health nurses, home support coordinators, and other health providers. In non-Aboriginal communities, those contacted included health care agency coordinators, hospitals, clinics and associated agencies.

Ontario's provincially-run Long-Term Care Division operates a number of home-based programs, including Home Support Services for the Elderly (home maintenance, Meals-on-Wheels, transportation, congregate dining, homemaking, friendly visiting, security checks, day programs and respite); Homemaker and Nursing Services; an Integrated Homemaker Program (to sustain and expand the scope of the family's capacity to continue to care for its members, including meal planning and preparation, cleaning and laundry, and personal care); Attendant Care Outreach (attendant care or personal care services); and a Home Care Program which provides health services in the home such as physiotherapy, respiratory technology, medical social work, nutritional counselling and others, in order to avoid or delay the need for institutional admission or to promote earlier discharge. Very few (if any) of these services are available on-reserve.

Significant changes to the current system are being made. Multi-service agencies will be established to create a single point of entry for individuals requiring long-term care services. These agencies will combine the function of case management/coordination with service delivery. A greater emphasis will be placed on community-based services. District Health Councils will now have the responsibility to develop long-term service plans, based on the community's needs and preferences and provincial guidelines and standards. District Health Councils will not include First Nations in the planning of the multiple service organizations.

Service Demand

Tables 1 and 2 summarize data on home care clients from ten First Nation and six non-Aboriginal communities.

The sample First Nation communities have a much higher proportion of clients with chronic illnesses and disabilities (11.7%) than the non-Aboriginal communities (4.3%). For example, although the populations of Moose Factory (semi-isolated) and its matched non-Aboriginal community of Moosonee are about the same, Moose Factory has 100 more clients with chronic diseases and disabilities.

The relative percentage of this group that is receiving home care services is about the same for both populations – 36.7% in the First Nation sample and 31.2% in the non-Aboriginal group. (**Note:** This comparison must be viewed with some caution since one-half of the First Nation sample did not provide this information.)

Table 1
Continuing Care Statistics in Selected Ontario First Nations

First Nation	Total population	# and % chronics/ disabled		# and % receiving services		Hours/ Week	Cost per hr.
N. Spirit Lake	235	18	17%	9	50%	77	$8.89/ $10.22
Summer Beaver	311	74	23.8%	N.K.		40	$8.89
Sachigo	333	79	23.7%	N.K.		146	$8.89
Bear Island	222	54	24.3%	54	100%	30	$8.00
Sandy Lake	1600	181	11.0%	N.K.		374	$8.89/ $9.35
Moose Factory	1838	300	6.3%	N.K.		N.K.	$10.54
Shshwng	153	45	29.4%	45	100%	35	N.K.
New Credit	762	126	16.5%	28	22.2%	74	N.K.
Tyendinga	3790	203	5.4%	30	15.0%	440	$166,100 (annually)
Total	**9244**	**1080**	**36.7%**	**166**	**36.7%**		**$8.00 $10.54**

Note: Data was not available from the First Nation of Lac La Croix.

The hourly wages received by homemakers in the First Nation sample ($8.00 to $10.54) were substantially lower than those in the non-Aboriginal sample ($9.85 to $16.31).

The First Nations sample received an average of four hours of services per client compared to 2.5 hours per week for the average non-Aboriginal client. However, without reference to the severity of the disability or need of each client, it is difficult to draw conclusions from this comparison.

Availability of Continuing Care Services

Most of the First Nations communities identified the welfare administrator as the person who assessed and allocated the type and time of units of services required. However, in some communities, health committees, community health nurses and visiting physicians may also be involved. There was no indication that these staff had received any training in assessment and no criteria was identified for assessment and allocation of time units.

Table 2
Continuing Care Statistics in Selected Ontario Non-Aboriginal Communities

Non-Abor. Community	Total population	# and % chronics/ disabled		# and % receiving services		Hours Week	Cost
Temagami	1800	4	<1%	4	100%	24	$28.00 (nurse)
Ear Falls	1297	12	<1%	12	100%	26	$16.31
Atikokan	4100	26	<1%	26	100%	43	$16.00
Moosonee	2000	398	19.5%	46	12%	93	$9.85 $10.82
Silver Water	167	10	6.0%	9	90%	N.K.	N.K.
Hagersville	2500	63	2.5%	63	100%	198	$14.99
Total	**11864**	**513**	**4.3%**	**160**	**31.2%**		**$9.85 $16.31**

However, the report states that in the First Nation communities eligibility for homemaker services is in accordance with the Ontario Homemakers and Nurses Services Act.

With respect to homemaking services, although the population of the non-Aboriginal community of Hagersville is three times greater than that of the New Credit First Nation, its matched First Nation community, New Credit has twice as many chronically ill and disabled clients. Despite this difference, New Credit clients receive less than half the hours of homemaking services as those in Hagersville.

A comparison of home care services in each group of sample communities reveals the following:

- Both groups of sample communities provide homemaker services. However, the range of homemaking services in First Nation communities is less than in non-Aboriginal communities;
- In the area of personal care services, the differences between First Nation and non-Aboriginal communities are striking. In First Nations, responsibility for personal care lies almost exclusively with family members. In contrast, personal care in non-Aboriginal communities is shared among family members, trained homemakers and, in some cases, home care nurses;
- Comparatively, non-Aboriginal communities tend to have higher relative percentages of Type 2 and 3 clients combined (for example, 31% in Atikokan and 50% in Moosonee). This appears to reflect greater access to personal care and home health care services, which allows more of these clients to remain in their communities;
- Clients in non-Aboriginal communities have much better access to a fuller range of health care services than those in the First Nation sample, with the exception of non-isolated Aboriginal communities. For example, in Sandy Lake First Nation, podiatry and speech therapist services are

not available, while in the matched non-Aboriginal community of Ear Falls, clients have access to physiotherapy and speech/ occupational therapy as needed. Bear Island First Nation clients (isolated) receive nursing services twice a month, whereas its matched non-Aboriginal community of Temagami provides its clients with two nursing visits per week;

- All First Nation communities, except for the non-isolated, expressed the need for increased hours of health care services;
- Community support services such as meal delivery, transportation, friendly visits, adult day care and respite services are lacking in First Nation communities when compared to non-Aboriginal communities;
- Eligibility criteria in First Nation communities were broader and more general in scope; and

Most non-Aboriginal communities in the sample did not have any special programs or provide any consideration for First Nation clients.

Training

All non-Aboriginal communities provide certified training for their homemakers, part of which includes training in the provision of personal care services. In contrast, none of the remote-isolated and isolated First Nation communities provide training for their homemakers. Training is provided in semi-isolated and non-isolated First Nation communities, probably reflecting their proximity to local colleges.

Service Gaps

The Ontario regional report also provided a comparison of actual needs to services provided:

- Additional home support services are needed in communities where the workload is heavy due to a lack of running water, electricity and heating systems;
- In most First Nation communities, it was stated that the existing home support and homemaking services do not meet the demand, especially for chronically-ill elderly clients;
- Information regarding the provision of special equipment such as canes and walkers is not available;
- There is an expressed need for a senior citizens' complex for short-term residential care. The complex would be used by clients who do not need hospitalization, but still require supervised home care;
- More home nursing services are required;
- Reserve health centre staff are being accessed by off-reserve clients because the public health and advocacy functions are culturally appropriate and accountable to First Nation councils;
- Homemakers have difficulty providing personal care services due to lack of training; and
- Meals-on-Wheels, transportation services and adult day care were identified as needs.

Manitoba Regional Summary Report

Introduction

In the Manitoba region, eight reserve communities were matched to eight non-Aboriginal towns. There were three pairs of isolated communities, two pairs of semi-isolated communities and three pairs of non-isolated communities. The nurse-in-charge for the reserve communities and the case coordinators from the provincial government's Home Care Program were contacted and asked to provide information regarding their home care services and clientele.

The provincial government in Manitoba operates a Continuing Care Program which includes services to seniors, a home care program and a nursing care program. The program has the following features:

- A single entry point from multiple referral sources. Referrals can come from the general public or health care providers. A comprehensive functional assessment is performed by a case coordinator who determines client needs and arranges services, which may include homemaking, personal care attendants, and nursing care, as well as supplies and equipment;
- Clients are reassessed at specific intervals. Prospective nursing home entrants are assessed at the same time;
- The policies are set centrally and the program is administered regionally; and
- The provincial program does not provide services to clients on-reserve but will provide all its services to First Nation people living off-reserve.

Service Demand

There were 222 clients identified in the eight First Nation communities included in the Manitoba regional study. This represents a utilization rate of 2.4% out of a total population of 9,421. There were 239 clients identified within the non-Aboriginal communities (population = 9,210) for a utilization rate of 2.6%.

The First Nation home care patients are younger than their provincial counterparts. For the provincial population, 77% of home care clients are over the age of 65 years. However, 49% of all home care clients in the First Nation sample were 65 years of age or older. About 32% of all people 65 years of age and older in the First Nation communities were receiving some kind of home care service.

The Manitoba regional report notes that there is an increased quantity and diversity of needs in First Nation communities:

> "In addition to serving the frail elderly, home support services are needed for children and young adults with congenital malformations, fetal alcohol syndrome, injuries and chronic mental and physical diseases such as diabetes with attendant amputations and end stage renal failure." (P.5)

Availability of Continuing Care Services

None of the reserves surveyed has an integrated home care program. None has personal care attendants. There did not appear to be any case coordination of clients or formal training of home care staff. Nursing services are supplied through the

nurse-in-charge at the nurse's or the attending physician's request. There is no dedicated home care nursing staff.

Overall, the reserve communities do not have an organized home care program. Services are provided by at least two agencies and are not coordinated. There do not appear to be uniform criteria for accessing services and it is unclear how they are managed. Necessary equipment is obtained through physician's prescription via the Non-Insured Health Benefits Program, although many clients may not be aware of how to access such services. In addition, the services are not provided on a continuum and are not integrated with the nursing home program. There appears to be ineffective, inefficient and inequitable use of scarce resources.

As indicated in Table 1, although the total population of each sample group is about the same, there are some striking differences in the utilization of home care services between the two groups of communities. The First Nation communities were utilizing almost 350% more homemaker services than the non-Aboriginal group. This probably reflects the extra work which results from a lack of running water, washing machines and central heating in many homes and the higher rates of morbidity among First Nation people. Homemaker service involves activities such as hauling water and cleaning, and usually does not include support for daily activities such as bathing and mobilization.

Secondly, personal care services are almost non-existent on-reserve (28 hours of service per week), although they account for a majority of off-reserve home care services

Table 1
Required and Provided Home Care Services (Hours of Service per week) for Selected Communities in the Manitoba Region

	First Nation Communities (Population = 9,421)	Non-Aboriginal Communities (Population = 9,210)
Homemaker Services:		
Required	1944.00	369.25
Provided	1207.25	369.25
Difference	736.75	0
Personal Care Services:		
Required	39.00	1292.00
Provided	28.00	1292.00
Difference	11.00	0
Health Care Services:		
Required	169.14	79.25
Provided	37.76	79.25
Difference	131.38	0
Total Home Care Services		
Required	2,152.14	1,740.50
Provided	1,273.01	1,740.50
Difference	879.13	0

(1292 hours of service). This probably reflects the complete absence of personal care attendants on-reserve and the fact that personal care is probably being done entirely by family members. It also reflects the lack of an integrated home care program and the lack of comprehensive case management of home care clients.

Three of the First Nation communities surveyed did not provide any home nursing services, in contrast to only one non-Aboriginal community. There appears to be an increasing need for specialized home nursing services due to early hospital discharge and the need for post-operative services such as dressing changes, dialysis, total parenteral nutrition, and in-home intravenous treatment.

In the First Nation sample, a variety of people were identified as the persons responsible for assessing and allocating home care service units, including the community health nurse, Band administrator, welfare administrator, visiting physician, and the "band". In the non-Aboriginal communities this responsibility was carried out by either the case coordinator or the public health nurse.

Most of the First Nation communities in the sample did not have a formula or protocol to determine services and units of time for clients, although one community indicated that it uses the MSB Chronic Disease Registry, while another utilizes the nursing service activity reports. In its discussion of the findings in its region, the Manitoba report also notes that there is a concern that Band members on the whole know little about available home care services and have difficulty accessing them.

The per capita hours of service per week (for all home care services) at 0.14 hours per week is lower on average among First Nation communities, than for non-Aboriginal communities, where it averaged 0.19 hours per week.

The hourly cost of homemaking services in the First Nation communities is in the $5 to $5.50 range, compared to $8 to $10 in the non-Aboriginal sample.

The total spending by both MSB and Department of Indian Affairs and Northern Development (DIAND) on home care services in the eight First Nation communities was $429,408. On a per capita basis, costs were:

- DIAND per capita $40.49
- MSB per capita $ 5.09
- Total per capita $45.58

The Manitoba government has stated that expenditures in continuing care services have increased by 100% in the past five years due to increasing demand. In 1992/93, the per capita provincial expenditure for off-reserve residents was $397.98. This compares to an on-reserve federal per capita expenditure of $191.58, a disparity of over $206 per capita. Stated another way, on-reserve per capita continuing care expenditures are only 48% of those available to off-reserve residents.

There was no consistent pattern of utilization based on the size or the isolation of the community.

The provincial government does not provide continuing care services to First Nation clients living on-reserve but will provide its full complement of services to First Nation people living off-reserve.

Training

None of the homemakers working in the First Nation home care programs have any formal training. In the provincial communities, personal and home care workers are trained in a home support worker course and a health care aide course through an accredited program at a provincial community college.

Service Gaps

A final comparison is the difference between the current level of home care services and the level of services that are required to meet clients' needs within both sets of communities. The current level of service is meeting 100% of client needs in the non-Aboriginal community sample (see Table 1). First Nation clients, however, are receiving only:

- 62% of their homemaker requirements;
- 72% of their personal care requirements; and
- 22% of their home nursing requirements.

On average, the communities in the First Nation sample are receiving only about one-half (51%) of their service requirements in these areas.

The Manitoba report identifies the following current barriers:

- Inadequate and fragmented services due to jurisdictional issues within the federal government, including DIAND, MSB and First Nations, and jurisdictional issues between the federal and provincial governments;
- Current economic constraints leading to cuts in existing provincial programs;
- Lack of community awareness and multiple political priorities for First Nations; and
- Current decentralization through transfers which may interfere with a regional program.

Saskatchewan Regional Summary Report

Introduction

In the Saskatchewan region, a number of methods were used to provide both a qualitative and quantitative summary of the home care situation of several First Nation communities in the region. Information was also provided about the provincial system, its funding formula and training resources. The information that was obtained from both First Nation communities and provincial sources must be viewed within the context of health reform that is proceeding within the province of Saskatchewan. The demands on home care services are increasing rapidly and will have a major impact on the home care program both on and off-reserve.

Statistical information from the MSB Chronic Disease Registry was analyzed for four First Nation communities in the region. This included data on the type of chronic condition and the age and gender of the chronic population. Additional information on the organization of home care services was also provided for four First Nation communities and for two non-Aboriginal communities. A more in-depth analysis of Thunderchild First Nation and the nearby non-Aboriginal community of Glaslyn was also completed.

Service Demand

Extensive data was provided on the number and condition of First Nation persons with chronic diseases. The Chronic Disease Registry maintained on First Nations in Saskatchewan is one of the most comprehensive and current in Canada. The Registry can identify both those with chronic diseases and those over sixty-five years of age. In the absence of comprehensive assessments of client needs, it has been assumed that those on the Chronic Disease Registry are most likely to require home nursing and home support services. The Registry also provides an assessment by the community health nurses of the degree of home care services needed: none, mild, moderate and severe. It should be noted that the provincial health care system does not maintain a Chronic Disease Registry by community.

Table 1 provides data on the number of persons with chronic conditions and disabilities in four First Nation and two non-Aboriginal communities. On average, 5.9% of the First Nation sample had chronic conditions or disabilities. Of these, between 15% and 30% required some form of home health care service.

Under initial analysis, it would appear that the home care needs of those persons living on-reserve in the sample communities are less than those in the non-Aboriginal communities. However, Black Lake and Southend are isolated communities, where most personal and acute care treatments are performed in the nursing station. Furthermore, the communities of Shellbrook and Carlyle have access to comprehensive home care services, whereas the range of services available on-reserve to the First Nation communities is very limited. As well, the relative number of people over 65 years in the non-Aboriginal communities is over four times that of the First Nation communities.

Table 1
Continuing Care Statistics in Selected Saskatchewan First Nation and Non-Aboriginal Communities

Community	Total population	# and % chronics/ disabled		# and % requiring service	
First Nation:					
Black Lake	1091	19	1.7%	8	42%
Southend	824	43	5.2%	5-10	12-23%
Muskeg Lake	383	20	5.2%	8	40%
Whitebear	628	90	14.3%	4-25	4-28%
Non-Aboriginal:					
Shellbrook	1271			30-40	
Carlyle	1189			30-50	

Table 2
Chronic Conditions Among Selected Saskatchewan First Nation Communities by Age Groups and Major Chronic Diseases

First Nation	# of Chronics	#and % by Age Group		# and % by Condition	
Thunderchild	65	<25 – 14 (22%)		Cardiovs	17 (26%)
		25-64 – 32 (49%)		Diabetes	15 (23%)
		65+ – 19 (29%)		Arthritis	12 (18%)
Muskeg Lake	20	<25 – 1 (5%)		Cardiovs	8 (40%)
		<25-64 – 8 (40%)		Diabetes	7 (35%)
		65+ – 11 (55%)		Arthritis	3 (15%)
Black Lake	19	<25 – 4 (21%)		Cardiovs	5 (26%)
		25-64 – 13 (68%)		Diabetes	2 (11%)
		65+ – 2 (11%)		Arthritis	1 (5%)
Southend	43	<25 – 6 (14%)		Cardiovs	17 (40%)
		25-64 – 25 (58%)		Diabetes	12 (28%)
		65+ – 12 (28%)		Arthritis	5 (12%)
Total	**147**	**<25 – 25 (17%)**		**Cardiovs**	**47 (29%)**
		25-64 – 78 (53%)		**Diabete**	**36 (28%)**
		65+ – 44 (30%)		**Arthritis**	**21 (14%)**

In Table 2, data on the ages and types of disabilities of persons with chronic conditions in four First Nation communities is provided. In these First Nation communities, only 30% of those with chronic diseases are aged 65 years or older. Seventeen percent are under 25 years of age and 53% are between 25 and 64 years of age. This contrasts with the provincial continuing care program, where 83.8% of clients are 65 years of age or older (Continuing Care Branch, Saskatchewan Health, Statistical Supplement to the Annual Report for the Year Ended March 31, 1991).

Cardiovascular disease is the most common chronic condition in these sample communities, affecting 29% of chronic care patients. Diabetes affects 28% and arthritis affects 14% of persons with chronic conditions. Together, these three conditions account for 71% of the chronic care caseload of these First Nation communities. This analysis does not however provide an indication of the degree of service required by First Nations which, based upon experience, is greater than that of non-First Nation peoples with similar conditions.

Table 3 provides an in-depth look at the home care services in the communities of Thunderchild and Glaslyn.

In this comparison, 2.8% of the on-reserve population are receiving home care services as compared to 6.5% of the non-Aboriginal community population. The Thunderchild First Nation community indicated that there was a current shortfall of 85 hours of home care service per month. This discrepancy may be accounted for by the varying age distribution, with less than 3% of the Thunderchild population being over the age of 65 years of age and 16% of the Glaslyn population being over 65 years of age.

Both communities have home care administrators with several years of home care experience in the provincial system who can provide assessments and case management. The program model at the Confederation of Tribal Nations is based on the provincial model. It should also be noted that the nursing services provided at Thunderchild are palliative and the gap is related to acute care nursing services. All of the staff providing services meet the training standards of the provincial program and are covered with appropriate liability insurance.

Availability of Continuing Care Services

The Saskatchewan Home Care Program delivered in southern Saskatchewan was initiated in the late seventies and has evolved into a viable and cost-effective alternative to institutional care.

Provincial policies and standards have been developed by the province and implemented by district boards, now incorporated into provincial health districts. All districts provide referral and assessment services, care coordination, home support, home nursing, meals, transportation, respite and palliative care. The availability of auxiliary services such as physiotherapy, occupational therapy, chiropody, respiratory therapy and mental health services varies from district to district.

The services are available to all persons living off-reserve and in the southern part of the province. First Nation people are eligible for provincial home care services if they live off-reserve and can either personally pay or arrange payment for services received from either DIAND or, in some limited circumstances, MSB for certain approved home nursing services.

Table 3
Comparison of the Thunderchild First Nation Community and the Non-Aboriginal Community of Glaslyn

	First Nation	Non-Aboriginal
Community	Thunderchild (rural/non-remote)	Glaslyn (rural/non-remote)
Affiliation	Confederation of Tribal Nations	North Battleford home care district
Population	667	460
# of persons receiving care	19 (2.8%)	30 (6.5%)
Services provided:		
Home support	117.5 hrs/mth	189.0 hrs/mth
Nursing	46.0 hrs/mth (includes travel time)	51.5 hrs/mth
Assessment and care coordination	28.5 hrs/mth	46.0 hrs/mth
Service gap	– shortfall of 85 hours of service per month – meals-on-wheels – palliative care – respiratory therapy – physiotherapy – occupational therapy – access to continuing care respite	– mental health – poor referral system – respiratory therapy

The provincial funding formula for home care services has evolved over the years. Initially, the funding formula was based on the population of a district, the number of people over 65 years of age and the number of people over 75 years of age. Also, an administration factor of approximately 2.6% of the total budget was included. Over the years the formula has become more complex and now includes such factors as the number of acute care and long-term care beds within the district. Percentage increases and/or supplements are provided based on the districts' acute care, supportive and palliative care requirements. The provincial funding formula is thus a combination of needs-based and population-driven criteria. The funding base is also supplemented by fees paid by clients on a fee structure that incorporates both income levels and service requirements. Clients are never exempted from payment.

In 1991/92, the Continuing Care Division of Saskatchewan Health reported the following volume of home care clients by service area:

Service	Clients		Average monthly clients	
	Number	Percent	Number	Percent
Nursing	10,343	53.7	4,885	41.0
Meals	4,046	21.0	1,966	16.5
Home maintenance	776	4.0	226	1.9
Homemaking	12,945	67.2	8,592	72.2

The provincial home care program delivered in northern off-reserve communities is the mandate of Northern Health Services, an arm of Saskatchewan Health. The accessibility and administration of these services are very different from the service provided in the south. The funding allocation uses a per capita formula which is approximately $50 per capita. There is no universal access to home care services by northern residents. The home care program is accessible to clients living in well-established larger communities with access to other health care services. The more remote, smaller communities have either seasonal or limited home care services.

Within the last two-and-a-half years, some federal funding has become available for the provision of on-reserve home care programs. Many First Nation communities and tribal councils accessed resources from the Seniors Independence Program to complete a needs assessment for home care services and submitted proposals to both HC/MSB and DIAND. Both of these federal departments have agreed to a joint funding regime that is based on a per capita formula of $60 for the on-reserve population (DIAND $50 and MSB $10). DIAND has recently provided some care coordination/administration resources to some tribal councils on a limited and temporary basis. Training of home care workers and the availability of training continue to be issues.

From the outset, First Nation communities have indicated that this funding formula is inadequate, as it allows only for the delivery of limited home support services and does not provide for care coordination, administration, supplies, home nursing or training of home care staff. DIAND is funding the program under its Adult Care Program, which has very specific limitations. MSB's Saskatchewan Regional Office has provided its portion of the funding from the Non-Insured Health Benefits Program.

There are currently two tribal council-level on-reserve home care programs in the Saskatchewan region. The remainder of on-reserve home services are delivered by individual First Nation communities.

Saskatchewan First Nation communities have an active regional First Nation Home Care Working Group that meets quarterly to discuss common issues and plan strategies to increase services. Saskatchewan First Nations have also obtained funding through the Seniors Independence Program to develop procedures and recording forms for care planning, coordination and assessment. In addition, a home care assessment manual and guidelines for standards development have been

developed and distributed throughout Saskatchewan. The objective of all these efforts is to promote the development of services that are safe, comprehensive and provided by trained staff.

Training

Training programs for the delivery of provincially-operated home care services has been developed by the Saskatchewan Institute of Applied Sciences and Technology (SIAST) and are delivered by regional colleges throughout the province. There are two training programs: the home health aide/ special aide program and assessment training for registered nurses.

1) *Home Care/Special Care Aide Program.* A pre-requisite to employment by the provincial home care districts is certification as a Home Care/Special Care Aide for persons providing either homemaking or personal care to clients. A person with both home care and special care aide training can then be employed by both special care homes and home care districts.

   Costs for this training are either incurred by the individual or through sponsorship through an employment agency. The length of the course is approximately 25 weeks (900 hours), which includes a 300-hour practicum in special care homes. It can be taken either on a full-time basis or part-time over a two-year period. The minimum entrance requirement is a Grade ten education.

2) *Assessment Training.* During the early years of the provincial home care program, this training program was provided to persons who had completed the special care aide training. The purpose was to facilitate the performance of client assessments that would maximize the use of the service, minimize the costs and promote the independence of clients.

   Over the years, provincial home care and continuing care standards have been revised and now require the ability to complete client assessments and ongoing care reviews by registered nurses certified in assessment. Therefore, the current assessment training program in Saskatchewan is for registered nurses only. Costs for the training are incurred by the employer.

Only one tribal council in Saskatchewan has organized and delivered a home care/special care aide training program to 15 students on a full time basis. The cost of this 32-week program (which also incorporated some lifeskills training) was $77,740. These costs included instructors' fees and travel, monitoring by SIAST staff, operational costs, supplies and administrative costs charged by the provincial system for the use of its program and for the accreditation of students. Provincial accreditation is important since trained accredited personnel can be employed by both First Nations and provincial institutions.

While the provincial assessor training program is comprehensive, it is neither culturally appropriate nor does it support assessment in a language other than English. A preliminary analysis by both First Nations and SIAST of revisions required concluded that the development of modules to refocus the training course for persons who do not have nursing training could be completed for approximately $18,000. These revisions would enable trained First Nation staff to complete the assessment in a First Nation language and in a manner that is both culturally appropriate and effective for care planning.

Other training requirements that were identified for the delivery of a comprehensive and safe home care program include ongoing in-service requirements that may focus on abuse and its identification, updates on diabetes and other chronic disease conditions. In addition, there are specialized training requirements for treatment such as renal dialysis, parental alimentation, palliative care, pain management and others.

Less than 5% of workers currently providing homemaking or personal care on-reserve have completed the training program required to meet provincial program standards (JLS Associates and Adrian Gibbons and Associates, Saskatchewan Aboriginal Health Careers Study, June 1993) and many of the on-reserve home care staff are currently enrolled in the training program on a part-time basis.

Service Gaps

With the exception of one tribal council and one First Nation community, the on-reserve home care services provide primarily homemaking. Client assessments, care coordination and case management services have not been funded. The North Battleford District Provincial Home Care Director has noted that it has been the experience of the provincial program that "the more care coordiation hours, the less service required, as case management and referrals are more comprehensive."

Federal and Band-employed nurses throughout the region have identified a dramatic increase in clients returning to First Nation communities with highly specialized acute care nursing requirements. These include intravenous therapy, renal dialysis, high risk pregnancy management, acute post-operative care, and dressing changes. The substantial gap in home care services is matched by a substantial need for more training of home care staff.

Furthermore, with the closure of both acute care beds and long-term beds throughout Saskatchewan as a result of health care reform, access to respite care and/or institutional care is decreasing. Because of this fact, and the cultural preference of First Nations to keep Elders at home in the community, the current focus of the home care programs of many First Nation communities is the provision of homemaking support services to the elderly.

Alberta Regional Summary Report

Introduction

The Alberta region provided data on six First Nation communities and one provincial health unit. The data was based on a survey done in November, 1992. Also included from the Alberta region was a report on home care at Hobbema, a summary report on the First Nation People with Disabilities Conference hosted by the Yellowhead Tribal Council, and copies of the **Aboriginal Persons with Disabilities Survey (June 1992)** and **Removing Barriers: An Action Plan for Aboriginal People with Disabilities (September 1993)**, which were prepared by the Alberta Indian Health Care Commission for the Premier's Council on the Status of Persons with Disabilities.

The Alberta Department of Health made home care "a program for all Albertans who require community care regardless of age or disability." In 1991, the program expanded so that persons under 65 years of age could access support services regardless of a need for professional services and without a medical referral. Home Care has significantly increased under its expanded mandate and is now the largest program in the regional health units and the largest community care program in the health and social service system in Alberta.

Home care nurses in the provincial system assess client needs, develop a care plan, provide nursing services and co-ordinate the other services required to maintain a client at home. Nursing services are provided to early discharge clients, including post-natal, post-surgical, palliative care, chronic care (including diabetics), geriatric surveillance for the frail elderly, and foot care. Physiotherapy and occupational therapy are available. Home support aides and personal care aides provide homemaking and personal care. Home support aides take an accredited eight-month course and are supervised by a registered nurse. A comprehensive referral and liaison program is available, including services in the areas of hospital discharge planning, mental health, self-directed care, Medication Assistance Program for clients in Seniors Lodges, and others.

The province does not extend continuing care services to First Nation communities, stating that on-reserve residents are a federal responsibility. As part of Alberta Health's *A Three-Year Business Plan* (February 24, 1994), the province is cutting acute care beds by 42% and increasing day surgery and early discharges. The resulting impact on First Nations has been increased non-insured health benefit costs, longer waiting lists for surgery and the erosion of on-reserve public health programs because of increased demand for nursing care at the community level.

Service Demand

Table 1 provides an overview of selected continuing care data in the First Nation communities chosen for the consultation. The number of chronics and disabled is very high, fully 11% of the population in these communities. Approximately 43% of chronics and disabled require home care services.

Table 1
Continuing Care Statistics in Selected Alberta First Nation Communities

First Nation Community	Total population	# and % chronics/disabled		# and % requiring services	
Hay Lakes	1069	52	5%	48	92%
Fort Chipewyan	726	120	17%	6	5%
Peigan	1550	179	12%	100	56%
Beaver Lake	516	26	5%	N.K.	
Garden River	351	31	9%	11	35%
Meander River	400	100	25%	N.K.	
Total	**4612**	**508**	**11.0%**	**165**	**13%***

September 1992

*Includes only those communities reporting this information.

The report also notes an increase in home care requirements for early discharge and terminally ill clients. Clients are returning to their communities requiring dressings, care of drains, dialysis and pain management. In communities with nursing stations but with no personal care services, community health nurses try to cope by having clients come to the health clinic for these services, although this is not possible in all cases. In communities without treatment centres, there are no such options.

The situation as of September 1993 with respect to early discharge was described as follows:

- Hay Lakes: Increasing by two to three per month.
- Fort Chipewyan: Increasing; day surgery is up; young mothers discharged two to three days after delivery; orthopaedic up; current number is six to ten per month.
- Peigan: Increasing by three to four per month; Pincher Creek Hospital lay-offs and some bed closures imminent (38 bed hospital).
- Beaver Lake: Unknown.
- Garden River: No increase evident; one infant in last two months.
- Meander River: Increasing by two to three per month.

The number of clients requiring palliative care is also increasing in all First Nation communities in the Alberta sample. In the case of palliative care, personal care services become more significant and much more time consuming. The time required for the daily handling of these cases can range from an hour to a number of visits daily. Pain management and counselling become major care factors. With respect to palliative care for the terminally ill, the situation is as follows:

- Hay Lakes: One family unable to cope – client hospitalized and died in last six months.

- Fort Chipewyan: Five to six terminally ill annually; daily visits, time intensive pain management.
- Peigan: Three palliative care in last six months.
- Beaver Lake: None currently.
- Garden River: None currently.
- Meander River: Two since January 1993; families try to cope.

Hobbema Reserve, with an on-reserve population of approximately 8,000, provided information on caseloads and visits by month and clients by health problem from its home care program for the years 1990/91 and 1991/92. As outlined in Table 2, the average number of clients per month increased by 28% from 1990/91 to 1991/92 (from 43 clients to 55 clients). Client visits by home care staff increased by approximately 13%.

Table 2
Hobbema Indian Health Care Home Care Department

Caseloads by clients and visits by month, 1990/91 and 1991/92

	1990-91		1991-92	
	No. of Clients	No. of Visits	No. of Clients	No. of Visits
Apr	42	90	47	110
May	42	117	57	176
Jun	35	107	51	123
Jul	56	142	54	121
Aug	41	101	60	125
Sept	38	59	54	103
Oct	41	87	55	134
Nov	41	100	54	84
Dec	41	89	56	109
Jan	51	139	62	138
Feb	43	102	56	81
Mar	48	116	58	116
Total	**519**	**1249**	**664**	**1420**
Average	**43**	**104**	**55**	**118**
Percent Increase 91/92 over 90/91		28%	13%	

Table 3 shows that the most common chronic conditions requiring homemaker services were diabetes, heart problems and frailty among the elderly. However, the most demanding clients, i.e. those requiring the highest number of visits per client, were those with cancer and those requiring post-operative care. For example, cancer patients required almost five times as many visits as clients with diabetes. Post-surgery discharges required almost three times as many home care visits as the frail elderly.

The Hobbema Health Department found a total of 96 patients who required some kind of home care service after their discharge from hospital during the month of May, 1989 (Table 4). This represented an average of 31% of the discharges from area hospitals.

Table 3
Hobbema Indian Health Care Home Care Department

Permanent clients by health problem, 1991/92

Health Condition	No. of Clients (monthly average)	No. of Visits (monthly average)	Ratio – Visits/Clients
Diabetes	26.0	57.8	2.2
Heart	8.0	14.5	1.8
Fr. Eld.	7.2	11.4	1.6
Lung	3.3	5.1	1.5
Phy. Dis.	2.0	1.4	0.7
Cancer	1.2	12.2	10.2
Misc.	1.0	2.4	2.4
Pst. Surg.	0.6	2.7	4.5

Table 4
Hobbema Indian Health Care Home Care Department

Hospital discharges requiring home care for May, 1989

Hospital	No. of patients	No./% requiring home care	
Wetaskiwin (Medical Ward)	NA	33	
Wetaskiwin (Surgery)	50	7	(14.0%)
Wetaskiwin (Paediatric Ward)	119	35	(29.4%)
Ponoka	14	7	(50.0%)
Royal Alexander	2	0	(0%)
University of Alberta	8	6	(75)
Charles Camsell	0	0	
Red Deer	7	5	(71.4%)
Misercordia	3	3	(100%)
Grey Nuns	0	0	
Total	**203***	**96**	**(31.0%)***

*These figures exclude data from the medical ward of Wetaskiwin Hospital.

It is also interesting to note that of these 96 patients, 49 (50%) were under the age of 21 years. Approximately 31 or 32% were two years of age or younger.

The First Nation Persons with Disabilities Survey (June 1992), prepared by the Alberta Indian Health Care Commission for the Premier's Council on the Status of Persons with Disabilities, found the following:

- Of those responding to the questionnaire, 49% lived on reserves, 18% lived in Métis settlements, 18% lived in urban areas and 12% lived in rural areas;
- 77% said they were somewhat or extremely limited in their activities at home;
- About one-half of disabled First Nation people living on reserve or in settlements felt that personal support systems were not meeting their needs;
- Twenty-one percent (21%) of disabled First Nation people reported having great difficulty in getting access to needed health services. Over one-third of those living on-reserve had difficulty getting access to health services; and
- Only 17% of respondents reported having difficulty getting access to traditional healing.

Availability of Continuing Care Services

Table 5 provides information on the availability of various home care services to clients in the surveyed First Nation communities and the provincial health unit.

In five out of the six First Nation communities surveyed, no services were available in the areas of home care nursing, occupational therapy, or physiotherapy. None of the First Nation communities surveyed had access to respiratory services.

The Alberta data illustrates that access to homemaking varies greatly across the surveyed communities. It would appear that homemakers in First Nation communities often lack training, co-ordination and support. Personal care services were not available in any of the First Nation communities surveyed except for Peigan, where provincial services are available through a contractual arrangement. In Hay Lakes, a large community of almost 1100 people, five clients are currently in need of personal care assistance. However, no personal care services are available and only two homemakers are employed.

In the 1992 survey of home care needs on the Peigan Reserve, only 20% of those surveyed were satisfied with home care services, 7% were undecided, and 73% felt improvements were needed. Clients were least satisfied with physiotherapy services (55% felt their needs were not being met), homemaker services (52%), and dialysis (40%).

Training

The Alberta regional report noted "the lack of trained personnel (in First Nation communities) including: personal care aides, home care nurses and homemakers, which are integral to maintaining clients in continuing care in their home environment." One exception is the Peigan reserve, where there are six trained personal care workers.

Table 5
Continuing Care Statistics in Selected Alberta First Nation and Non-Aboriginal Communities

First Nation Community	Homemaker	Nurse	Respiratory Therapist	OT	Physio-therapist	Per Care
Hay Lakes	yes	no	no	no	no	no
Fort Chipewyan	yes	no	no	no	no	no
Peigan	yes	yes	no	yes	no	yes
Beaver Lake	yes	no	no	no	no	no
Garden River	no	no	no	no	no	no
Meander River	yes	no	no	no	no	no
Total	**5**	**1**	**0**	**1**	**0**	**1**
percentage	**83%**	**17%**	**0%**	**17%**	**0%**	**17%**

September, 1992
OT = Occupational Therapist
Per Care = Personal Care
Note: Nursing is provided by the provincial Chinook H[illegible]th Unit under contract. OT is provided by an independent practitioner paid for under NIHB. Physiotherapy is not provided on-reserve; clients travel to the nearest provincial health unit for physiotherapy services.

Non-Aboriginal Community	Home-maker	Nurse	Respiratory Therapist	OT	Physio-therapist	Per Care
North Eastern Alberta – Health Unit (St. Paul's)	yes	yes	yes	yes	yes	yes

September, 1993

In the provincial continuing care program, home support aides are required to take an accredited home support aide course. Home care nurses require active registration in the Alberta Association of Registered Nurses, a current certificate in cardio-pulmonary resuscitation, preferably with previous experience in rehabilitation, geriatric or home care nursing.

Service Gaps

In the main survey data above, the following issues were identified regarding home care services for the First Nation communities in the sample:

- At present, Medical Services Branch is not mandated for home care. Therefore, in order to provide a needed comprehensive home care program, this issue must be addressed;
- A need for improvements to current home-making services was identified including improved training, supervision and coordination and increased services for a number of communities;
- All communities identified the need for home care nursing;
- Adequate facilities to meet the social and recreational needs of the First Nation disabled are almost non-existent;

- Isolation caused by lack of accessibility to community facilities and members, inability to come to terms with one's disability, and other factors are causing many mental health problems among the disabled such as depression and anger. Appropriate mental health programs are not available;
- Lack of suitable housing was a consistent theme emerging in all three treaty areas studied; and
- Other issues identified included a lack of qualified staff in elders' lodges, a lack of health educators and nutritionists, especially for diabetics, and a lack of transportation for the disabled on most reserves.

The MSB regional office noted two additional problems in addition to those identified above:

- Lack of infrastructure funding regarding management and policy development; and
- Lack of discharge planning with acute care hospitals.

The Peigan Health Administration identified several problems of particular relevance to this study, including:

- Lack of proper training for homemakers;
- Insufficient communication between the Chinook home care nurse, homemakers and family members regarding services being provided;
- Concerns regarding legal liability for homemakers;
- Insufficient insurance for homemakers who transport clients; and
- Insufficient funding for services.

Other points noted by the Hobbema study included the following:

- The lack of home care nursing and home-making to supplement parental care on-reserve increases the problem of children being kept in hospital longer;
- The demand for home nursing services is supported by the cultural practice of keeping elders at home within the extended family;
- Community health nurses are only able to handle health centre visits and immunizations. Therefore, any type of treatment or assessment for equipment is done only for urgent needs, with minimal follow-up; and
- Coordinated support services such as home-making, Meals-on-Wheels and volunteers are not readily available and are not considered to be part of the home care team.

Pacific Regional Summary Report

Introduction

Two reports on the situation of First Nation persons with disabilities were prepared in the Pacific region. The first was an in-house study of four First Nation communities and four non-Aboriginal communities by Medical Services Branch, Pacific Region. The second was the Disability Needs Assessment Study undertaken by the First Nation Summit under contract to Medical Services Branch. The Summit surveyed five First Nation communities – Cowichan, Westbank, Canin Lake, Ahousaht and Seabird Island. No non-Aboriginal communities were surveyed by the Summit.

Additional data was provided by the **Report on B.C. Aboriginal People with Disabilities (1993)**, Final Report to the Royal Commission on Aboriginal People Intervenor Program (1992/93) by the B.C. Aboriginal Network on Disability Society (BCANDS). This report summarized the findings of a study of 362 B.C. Aboriginal people with disabilities.

Service Demand

Tables 1 and 2 provide information on the number of disabled persons within the First Nation communities who were part of the consultation. The MSB study found that 12% of its sample population were disabled. The First Nation Summit study found a similar percentage: 9.1%.

Table 1
Continuing Care Statistics in Selected Pacific First Nation Communities
MSB In-House Study

First Nation	Total Pop	# and % chronic/ disabled		# and % chronics/ disabled		Hrs/Wk Prov		Hrs/Wk Prov	
Iskut	326	47	14.4%	7	14.9%	HM	7.5	HM	12
						PC	0	PC	10
						HC	.25	HC	0.5
Takla	520	40	7.7%	6	15.0%	HM	27	HM	70
						PC	10	PC	14
						HC	0	HC	10
Kingcome Inlet	145	NA		8		HM	12		
						PC	0	NA	
						HC	0		
Kamloops Band	449	75	16.7%	15	20.0%	HM	80	HM	160
						PC	0	PC	15
						HC	5	HC	7.5
Total	**1,440**	**162**	**9.7%**	**28**	**14.7%**				

Iskut has identified ten individuals who will probably require personal care services within the next two to five years.
HM = Homemaker PC = Personal Care HC = Health Care

Table 2
Continuing Care Statistics in Selected Pacific Region First Nations
First Nation Summit Study

First Nation	Total On-reserve Pop.	# and % Chronics/ Disabled		# and % Male/ Female			% By Age Group		% Sv/Sg Dis*
Cowichan	1800	129	7.2%	M	48	37%	<20	10%	47
				F	81	63%	21-59	30%	
							60+	60%	
Canin Lake	350	59	16.9%	M	33	56%	<20	49%	10
				F	26	44%	21-59	34%	
							60+	17%	
Ahousaht	640	27	4.5%	M	17	63%	<20	4%	8
				F	10	27%	21-60	55%	
							61%	41%	
Westbank	250	80**	32%	M	30	38%	<20	12%	88
				F	50	62%	21-60	39%	
							60+	49%	
Seabird Island	320	12	3.8%	M	8	75%	<20	0%	100
				F	4	25%	21-59	38%	
							60+	42%	
Total	**3360**	**307**	**12.8%**	**M**	**136**	**53.8%**	**<20**	**15%**	**50.6**
				F	**171**	**44.2%**	**21-59**	**39.2%**	
							60+	**41.8%**	

* "Sv/sg dis" means severely disabled (unable to care for themselves) and significantly disabled (need assistance with some aspects of daily living).

** Estimates of the number of disabled persons living on the Westbank reserve varied considerably. The researcher felt that the estimate provided by the community health representative was the most accurate.

The summit study found that a majority – about 56% – of the disabled population in its study communities were female. About 16% were under 20 years of age, 38% were between 21 and 59 and 46% were over 60.

The summit also found that almost one-half (49%) of the disabled population in its sample communities were severely or significantly disabled to a degree that required some form of home health care intervention. This would mean that approximately 4.5% of the population of its sample First Nation communities would require some type of home health care service.

The most common causes of disability among residents of the Kamloops Band were diabetes and heart disease.

In the First Nation communities of Takla Landing and Kingcome, 67.5% and 50% respectively of their disabled/chronic population were under the age of 65 years. In the non-Aboriginal community of Port McNeill, only 20% were under 65 years of age.

The BCANDS study found that:

- About 59% of its respondents required assistance with some activities of daily life. These activities included bathing, feeding, dressing and washing;
- With respect to the issue of emotional well-being, 60% of respondents expressed an interest in attending cultural and social events but only 20% were able to attend;
- Approximately 49% of participants required medical equipment to conduct daily activities;
- Nineteen percent (19.1%) experienced difficulties in accessing required equipment;
- Respondents chose "home/nursing care" (12.2%) and "counselling support" (8.3%) as the most important services "to be examined as a first priority". "Support groups", "transportation" and "funding for equipment" were the commonly chosen "programs that should be started."
- About one-quarter (25.2%) of respondents said they were receiving homemaker services and a further 15.2% said they required these services. For nursing care, 5.9% were receiving the service and a further 6.1% required it. The figures for respite care were (receiving) 2.8% and (require) 4.7%. About 9.4% of respondents were receiving personal care services and a further 7.2% required this service.

Assessing service demand in the non-Aboriginal, matched communities was difficult, primarily because of the nature of the communities chosen. Two of the communities – Dease Lake and Mackenzie – are northern single industry communities that have very young working populations. Neither community has many elderly people. In MacKenzie, a community of about 6,000, there are only six clients who require home support services. These services are provided by local people who are hired by the Prince George Home Support Society, which also does the initial and follow-up assessments. Home care nursing is provided by a .32 Full-Time Equivalent (FTE) nurse who is employed by the local hospital under a hospital/community partnership program.

Dease Lake has a .2 FTE public health nurse who will do some home nursing care under an arrangement with her employer, the Skeena Health Unit. She has had only one recent palliative care client. There currently are no homemaking services in the community.

In the city of Kamloops (population 70,500), which was matched with the Kamloops Band, the average monthly caseload is 2010 or 2.9% of the population. The unit cost per hour of service (Monday to Friday) was $552. Specific information on the Kamloops caseload is as follows:

Table 3
Continuing Care Caseload, City of Kamloops

	Number of clients (percent of caseload)		Hours/Week	
Community rehabilitation (physio, occ therapy)	117	(5.8%)	105 Hrs	
Community home nursing care	259	(12.9%)	917 hrs.	(72.4%)
Long-term care:				
*Community	1153	(57.4%)	245 hrs.	(19.3%)
*Facility	481	(23.9%)		
Total	**2010**	**(100%)**	**1267 hrs.**	

In comparison, home nursing care in the Kamloops Band (see Table 1) makes up only 6% of the total continuing care service hours per week, while homemaking accounts for 94% of the total.

Port McNeill, a community of about 4500 on northern Vancouver Island, which is matched with Takla Landing, has 15 continuing care clients. Homemaker services, personal care and health care are available in the community. The community health nurse and physicians decide with the client or family member what type and length of care the client will need.

The Care Program Division of Capital Region District (CRD) Health on southern Vancouver Island is typical of the provincial continuing care programs offered throughout the Pacific region. The CRD provides a range of community-based health care services throughout the capital region, including home nursing care, long-term care, community rehabilitation, the quick response team, hospital liaison, and central intake. Referrals to programs such as home care nursing, long-term care or community rehabilitation may come from anyone.

In 1992, CRD Health provided services to the following numbers of clients through its major care programs:

Service	Clients	% of total population
Home nursing care	4,200	1.4
Home support services	6,000	2.0
Community rehabilitation	1,800	0.6
Quick response team	1,600	0.5
Hospital liaison	3,400 assessments of hospital patients in need of home support or facility services after discharge.	
Central intake	3,300 referrals for care programs were processed.	

In 1992, CRD health spent almost twice as much on home care nursing (21.1%) as it did on its public health nursing (12.6%).

It is also interesting to note that the palliative care caseload of the CRD's home nursing program has increased by 30% in the last 12 months.

Availability of Continuing Care Services

Table 4 indicates that there is a substantial gap between service demand and services provided in the First Nation communities of Iskut, Takla Landing and Kamloops Band. These communities are receiving only about 43.4% of the home care services that their band members currently require. Iskut and Kamloops Band have no personal care services, while Takla Landing has no home nursing care.

In the community of Iskut, homemaking services and some follow-up health care services are available in the community. Personal care is provided mainly by family members, with some services provided by the nurse or community health representative. At Takla Landing, homemaker services are provided by the Band, which in some cases includes some personal care services. No home care nursing is provided. At Kingcome Inlet, homemaker services are available but not personal care, extended care or home care nursing. At the Kamloops Band, the only home care service provided in the community is homemaking, which is operated by the Band.

In the non-Aboriginal community of Port McNeill, which was matched with the First Nation community of Kingcome Inlet, full services are provided in the areas of homemaking, personal care and health care.

In each of the First Nation communities, the time units and type of service required are allocated by the band social worker, CHR or CHN. One community says that it uses the DIAND schedule to set hours of time; the other three communities use an informal arbitrary allocation of units of time.

Table 4
Percent of Home Care Needs Currently being Met, Iskut, Takla Landing and Kamloops First Nations

Community	Hrs/Wk Provided		Hrs/Wk Required		% of Needs Currently Being Met
Iskut	HM	7.5	HM	12	62.5
	PC	0	PC	10	0
	HC	0.25	HC	0.5	50
Takla Landing	HM	27	HM	70	38.5
	PC	10	PC	14	71.4
	HC	0	HC	10	0
Kamloops Band	HM	80	HM	160	50
	PC	0	PC	15	0
	HC	5	HC	7.5	66.7
Total		**129.75**		**299.0/Hrs**	**37.6**

HM = Homemaker PC = Personal Care HC = Health Care

The average hourly wage for homemaking services is $7 at Takla Landing, $7.50 at Kingcome Inlet and $8 at Iskut and Kamloops Band. In the non-Aboriginal matched community of Port McNeill, the average cost per client was $28.71 per hour. However, a user fee is charged based on the client's ability to pay. In the city of Kamloops, the average hourly wage for nurses and therapists was $24.00/hour.

The First Nation Summit Disabled Needs Assessment Study studied the availability and the adequacy of continuing care services in its five sample communities. As indicated in Table 5, they found that homemaker and home nursing services were available in all communities but were rated by health care providers as "not adequate" or "inadequate" in almost all cases. Physiotherapy was available in some cases but occupational therapy and respite services were not available in any of the First Nation communities.

As indicated by a comparison of the data in Tables 3 and 5, services such as home care nursing, physiotherapy, and occupational therapy tend to be more available in non-Aboriginal communities than in First Nation communities.

Training

In the MSB study, none of the home/personal care service providers had any training. Nor was there any mechanism to determine the number of trained personal care workers required for the population.

In the non-Aboriginal community of Port McNeill, personal care workers take a ten-month training course at North Island College. These workers need this certificate of training to work in this area. The cost of this training is about $10,000 per person and includes a practicum in different health facilities and agencies in the area.

Service Gaps

The First Nation Summit Study noted some of the following needs for services for disabled First Nation people in its sample:

- Local health authorities in First Nation communities lack the authority to prescribe professional home care services to meet the needs of its members;
- Common obstacles cited by survey respondents regarding difficulties in accessing aides for mobility, safety and daily living included bureaucratic requirements and "red

Table 5
Availability and Adequacy of Home Care Services – First Nation Summit Study

Availability and adequacy rating of services
(Not Adequate 1 2 3 4 5 Very Adequate)

First Nation	Homemaker	Home nursing	Physio-therapy	Occup. therapy	Respite services
Cowichan	yes 1	yes 2	yes 2	no	no
Canin Lake	yes 1	yes 1	yes 1	no	no
Ahousaht	yes 3	yes 1	no	no	no
Westbank	yes 1	yes 1	no	no	no
Seabird Island	yes NR*	yes NR	yes 2	no	no

***Note:** "NR" means "not rated".

tape", accessibility, costs, lack of familiarity with available services, lack of knowledge on the part of Band staff of available services and reticence in dealing with non-Aboriginal agencies and personnel;

- Homemaking services were available in most communities but were inadequate to meet the needs of the disabled. Personal care services were inadequate in all communities. The need for personal care services is becoming more acute as the population ages in First Nation communities;
- Staff in the participating communities agree that an integrated or inter-agency approach to continuing care services should be developed;
- Housing improvements, including access ramps, widened doorways and renovations to bathrooms; and
- Poor or non-existent street lighting, unpaved roads, an absence of sidewalks and a lack of suitable transportation make it extremely difficult for people with mobility difficulties to move around the community.

Yukon Regional Summary Report

Introduction

In the Yukon region, visits were made to all First Nation communities in the region and to several communities in northern British Columbia. The first was designed for interviews with elders or disabled people and covered five basic human needs: shelter, nutrition, income and employment, mobility and transportation, and interpersonal relationships. The second questionnaire was designed for the providers of health services.

Availability of Continuing Care Service

Yukon Government-Non-Status Services

The Yukon Territorial Government (YTG) delivers a Yukon-wide Home Care Services Program staffed by home support workers, social workers and home care nurses. The majority of these services are provided to Whitehorse residents in their place of residence for the following reasons:

- Chronic illness and disability;
- Terminal illness;
- Acute illness not requiring hospitalization; and
- Care related to early hospital discharge.

(In Whitehorse, there are also home rehabilitation staff, i.e. occupational and physiotherapists who provide services).

Eligibility criteria are clearly stated in the program's mandate statement and referrals can be made through the Yukon Social Services Branch in Whitehorse or in the communities.

Under the job description for the home support worker, the duties of homemaking and personal care services are combined. Additional duties have been added to these positions, such as provision of emotional support; participation in case planning and monitoring; assistance with banking and paying bills; assistance with rehabilitation services; and some respite care. The job description does not include outdoor chores such as wood cutting or clearing walks. In the communities, the social worker is the case co-ordinator and arranges home support.

The salary range for a home support worker is $16.79 – $19.28 per hour. The position does not require, nor does it appear that any of the workers have taken, an accredited post-secondary level home care or personal care training course.

The Yukon Home Care program also employs home care nurses at $23.64 – $27.20 per hour. These positions require a degree or diploma in nursing with a certificate in community health nursing and two years experience working with seniors or the terminally ill, preferably in a community-based setting. Nurses, as well as social workers, act as case coordinators and home support supervisors who arrange home support services in Whitehorse.

Yukon Home Care also has a Vocational Rehabilitation Services Program which employs supported independent living workers to provide supported living services to persons with disabilities to enable them to maintain independent living (salary – $21 per hour).

In all rural Yukon communities, Yukon Home Care can provide home support services (if staff are available) to both First Nation and

non-Aboriginal clients. However, Yukon Home Care cannot duplicate the services and mandates of other agencies. The Department of Indian Affairs and Northern Development has the mandate to do the In-Home Adult Care program, which does not include home nursing services for Yukon First Nations.

As a result, the Yukon Government bills DIAND for the home support services it provides to status First Nation peoples. However, these expenses are not always fully recovered. It is felt by Yukon First Nations that the services received are inequitable and inconsistent with those received by the non-Aboriginal population.

Department of Indian Affairs-Status Services

The Department of Indian Affairs and Northern Development provides the funds for a homemaker program which is administered by individual First Nation Bands. Each Band administers these funds as service contracts on behalf of clients for basic housekeeping at $7 per hour. In keeping with the above statement, many Yukon First Nations have indicated that the homemaker program is inequitable, if not non-existent in many areas.

Rural Yukon First Nation communities are virtually without services in the areas of personal care, occupational health counselling and physiotherapy, career counselling, mental health, or counselling to deal with aging or disabilities. Only the larger communities of Whitehorse, Watson Lake and Dawson City offer respite services. Services for the deaf, such as sign language interpreters, are also non-existent. Public transportation services for the disabled are only available in Whitehorse.

Training

Formal training is provided to Yukon Government homemakers (they receive training as needs are identified to the Home Support Supervisors). Existing DIAND homemakers felt training was a necessity which would allow them to provide a more effective and meaningful service. An area identified for training is personal care skills; for example, the proper way to handle clients with mobility problems.

Service Gaps

In its preamble to recommendations, the Yukon regional report notes that:

> "responses to every general subject group of the questionnaires demonstrated that there is no area that does not require attention. Shelter, counselling, nutrition, income, employment, transportation, mobility, interpersonal relations, and general assistance and services all require initiatives to be undertaken."

The report, as well as ongoing discussions have generated a comprehensive set of recommendations covering all of these areas. Some of the recommendations which speak directly to the three service components of adult care identified by Medical Services Branch include the following:

- Funding levels to all Yukon First Nations for the provision of adult care services to the level of identified needs. These services, which should be comparable to those provided in urban areas, include:
  - Home care nursing services for early hospital discharge, palliative care, follow-up of chronic conditions and their complications;

  - Occupational/rehabilitation therapy, e.g. teaching ambulatory aides/devices, prosthetics;
  - Physiotherapy services, e.g. assessment and teaching to family, local paraprofessionals, and/or professionals;
  - Personal care services;
  - Homemaker services;
- An adult care training program for family members and home support workers should be developed in the Yukon and made accessible to all community residents;
- Regular scheduled home visits to all disabled people should be ensured;
- Guidelines regarding replacement of ambulatory devices should be reviewed in light of the shorter lifespan of wheelchairs and other devices in northern communities;
- A dietician/nutritionist should be engaged to develop a diet based on traditional food sources for First Nation persons with sugar diabetes and cardiovascular diseases;
- Interpreters should be made available for First Nation persons seeking medical attention;
- Community initiatives to enable Elders and the disabled to have readily accessible interpersonal/supportive contact, e.g. Elders residing on their own should have some kind of communication device readily available; and
- A fact sheet outlining the rights of the disabled should be developed and distributed to all First Nation disabled.

Consultation Analysis

In reviewing the regional consultation data, five major issues were identified: jurisdiction, funding, service delivery, program utilization, and access to rehabilitation services, training and liability. They are discussed in this section.

Jurisdiction

The national consultation process clearly shows that issues of jurisdiction and authority continue to limit the quality and scope of on-reserve continuing care services and to severely restrict the opportunities for future development in this area.

Provincial and territorial governments have developed comprehensive, full-service continuing care programs but, because of the provincial and territorial government positions that on-reserve services are a federal responsibility, provincial continuing care services are not extended to First Nation communities.

The federal Department of Indian Affairs and Northern Development (DIAND) has adopted a per capita funding approach that has enabled First Nations to provide basic homemaking services to some on-reserve clients. However, MSB does not have the mandate or authority to provide home care nursing or home-based rehabilitation services such as physiotherapy or respiratory therapy. Neither department provides any significant resources for client assessments, case management or staff training.

First Nations lack the financial resources, infrastructure and trained staff to provide comprehensive and culturally-appropriate continuing care services.

As a result of the current jurisdictional issues, there are significant gaps in the provision of continuing care services to First Nation people living on-reserve:

- home nursing care services and rehabilitation services are virtually non-existent;
- initial and ongoing assessments of client needs, case coordination and case management are weak, leading to inappropriate service allocation and inefficient resource utilization; and
- training and ongoing staff development of First Nation home care staff is extremely limited.

Furthermore, because of the jurisdictional confusion surrounding this issue and the severe underdevelopment of on-reserve services, First Nations have been unable to plan and participate in provincial/territorial health care reform and emerging health policies of the federal and provincial governments.

In September 1991, the Conference of Ministers of Health met to discuss Aboriginal health concerns with the leaders of the Assembly of First Nations, the Inuit Tapirisat of Canada, the Native Council of Canada, and the Métis National Council. The meeting resulted in the agreement to strike a Tripartite Working Group on Aboriginal Health.

The objective of the group was to recommend practical changes to improve the health of all Aboriginal peoples in Canada. The Report of the Group was presented to Ministers of Health in February 1994. There are twenty recommendations contained in the Report. These focus on mechanisms for the elimination of barriers to access caused by jurisdictional and eligibility issues;

identification of information priorities; and increasing Aboriginal involvement in all aspects of the health system. Many of the issues raised during the continuing care consultation were supported by the recommendations presented by the Tripartite Working Group on Aboriginal Health.

As the consultation process has revealed, a number of policies associated with provincial/territorial health reform, such as the implementation of regional governance and decision-making structures, have resulted in increases in the number of early discharges from acute care institutions, and concurrent increases in demand for community-based and home-based services. The impact on First Nation communities has been the erosion of community health programs because of a lack of coordination with provincial/territorial health facilities for discharge planning. This has led to requests for community public health programs to address chronic nursing care needs. However, First Nations lack the resources or service infrastructure to proactively respond to these developments.

First Nations and tribal councils involved in transfer and self-government processes, and those who have completed their agreements and are administering their own community health programs, have been unable to integrate continuing care services without the mandates and funding, resulting in increased pressures and gaps within existing community health services.

Funding

All regions stated that under-funding was a serious problem within the limited existing on-reserve continuing services.

Most provincial/territorial home care programs are spending approximately 40% of their continuing care budgets on home care nursing. MSB currently provides no resources in this area.

On average, provincial expenditures for the provision of continuing care services in the sample of First Nation communities was much lower than in the non-Aboriginal sample. For example, in Québec, the average hourly cost of home care services was:

Component	First Nation communities	Non-Aboriginal communities
Maintenance services	$ 7.35	$16.27
Personal care	$ 9.58	$20.86
Health care services (nursing care)	$25.29	$27.03

In the Manitoba Region, the hourly cost of homemaking services in the First Nation communities was in the $5 to $5.50 range, compared to $8 to $10 in the non-Aboriginal sample. In Ontario, the hourly wage received by homemakers in the First Nation sample was substantially lower than wages in the non-Aboriginal sample – a range of $9.85 – $16.31 compared to $8 to $10.54.

A number of problems were identified with the per capita funding approach used in the Saskatchewan Region. The current per capita formula provides only minimal resources for most communities. For example, a community of 400 receives only $24,000, enough to provide minimal homemaking services. The per capita approach does not address the actual

continuing care needs of First Nations, which can vary considerably from community to community depending on the characteristics of each community's case load. One or two clients with substantial needs can absorb most of the resources. No resources are available under the current formula for administration, case management, home care nursing or training.

Furthermore, the per capita approach lacks the flexibility of funding approaches such as health transfer or Alternate Funding Arrangements. In particular, under the current funding regime, there appears to be no coordinated case management or functional integration of continuing care resources with other health and social services in the community. There was widespread concern across all regions that even the minimal resources provided are not being used efficiently or effectively.

Delivery and Utilization

In all regions, provincial and territorial home care programs were identified as comprehensive full-service programs with clear legislated mandates, comprehensive standards, policies and assessment procedures, strong integration and coordination among programs and services, and efficient intake and referral systems.

In the case of First Nation communities, Manitoba region provided a typical assessment of the First Nation home care delivery system in that region:

> "None of the reserves surveyed have an integrated home care program. None had personal care attendants. There did not appear to be any case coordination or formal training. Overall, the reserve communities do not have an organized home care program. Services are provided by at least two agencies and are not coordinated. There do not appear to be uniform criteria for accessing services and it is unclear how they are managed. It is also unclear how individuals obtain equipment, if needed. In addition, the services are not provided on a continuum and are not integrated with the nursing home program. There appears to be ineffective, inefficient and inequitable use of scarce resources."

The regional consultation data confirmed the findings of several national studies that First Nation people have a much higher rate of morbidity and disability than the non-Aboriginal population. The Ontario Regional Report found that in its sample, First Nation communities have a much higher proportion of clients with chronic illnesses and disabilities (11.7%) than the non-Aboriginal communities (4.3%).

The First Nation Summit in British Columbia found that 9.1% of its sample population were disabled. In Alberta, the number of chronically ill and disabled people was also found to be very high, fully 11% of the population in the First Nation communities surveyed.

There was evidence of an increase in the numbers of First Nation peoples requiring home care nursing services due to early discharges from hospitals and for clients with terminal illnesses. Data from Hobbema in the Alberta region found that the clients needing the highest number of home visits were those with cancer and those requiring post-operative care.

Furthermore, because of higher rates of morbidity across all age groups, First Nations tend to have higher relative percentages of their home care caseloads in the 15 to 64 year old age group and less in the 65 years and older group. In the Manitoba study, for

example, approximately 51% of all home care clients were younger than 65 years of age. In British Columbia, the First Nation Summit found that 54% of its sample were under 60 years of age.

The utilization pattern is for First Nation communities to receive less home care services than non-Aboriginal communities. This is particularly true for personal care services, home nursing care and rehabilitation or support services such as physiotherapy and respiratory therapy, which are generally not available on-reserve.

The pattern for homemaking services was less consistent. In some cases, First Nation communities received more homemaking services per capita, while in others they received less. For example, in Québec, a higher proportion of clients in First Nation communities receive general maintenance (homemaking) services than in non-Aboriginal communities. However, the reverse is true with respect to personal care and health care services. For example, only 19.4% of clients were receiving personal care services in the First Nation sample, compared to 33.5% in the non-Aboriginal communities.

In First Nation communities, provision of personal care lies almost exclusively with family members. In contrast, personal care in non-Aboriginal communities is provided by family members, or purchased from trained homemakers, and in some cases home care nurses, on a means-test basis.

In the Manitoba region, although the total population of each sample group is about the same, there are some striking differences in the utilization of home care services between the two groups of sample communities. First, the First Nation communities were utilizing almost 350% more homemaker services than the non-Aboriginal group. This probably reflects the extra work which results from a lack of running water, washing machines and central heating in many homes and the higher rates of morbidity and disability among First Nation people. Personal care services were almost non-existent on reserves in the Manitoba Region (28 hours of service per week), although they accounted for a majority of off-reserve home care services (1292 hours of service per week).

In the Pacific Region, the First Nation communities of Iskut, Takla Landing and Kamloops Band are receiving only about 43.4% of the home care services that their band members currently require. In Manitoba, the corresponding percentage was 51%.

First Nation communities in Québec are more likely to identify factors such as "budget", "lack of trained personnel" and "lack of financial resources" as the major reasons for their services gaps, than their non-Aboriginal counterparts.

Dedicated home care nursing services were virtually non-existent in all surveyed First Nation communities across all regions. Some home nursing services are provided under the MSB NIHB program on a case-by-case basis.

Although home nursing care is basically non-existent on-reserve, it is a major program component of provincial continuing care programs. For example, the St. John's, Newfoundland Home Care Program spends about 40% of its total budget on home care nursing. In 1991/92, the Saskatchewan Department of Health provided home care services to 19,251 clients. Of these, 10,343 or 53.7% received nursing services. In 1992, the Health Department of the Capital Region District (CRD Health) in southern Vancouver

Island spent 21.1% of its total expenditures on home care nursing compared to 12.6% on public health nursing.

Access to Rehabilitation Services

In the Alberta region, in five out of the six First Nation communities surveyed, no services were available in the areas of home care nursing, occupational therapy, or physiotherapy. None of the Alberta First Nation communities surveyed had access to respiratory services.

In the survey of home care needs on the Peigan Reserve in Alberta, clients were least satisfied with physiotherapy services (55% felt their needs were not being met), followed by homemaker services (52%), and dialysis (40%).

The Québec regional report states that

> "it clearly emerges...that a larger number of health services are covered in non-Aboriginal communities than in First Nation communities, except for the community of Kahnawake. As an example, only the communities of Manawan and Kahnawake indicate that they provide occupational therapy and physiotherapy services, whereas these same services are provided by six and eight CLSCs respectively."

The Québec Report also notes that non-Aboriginal communities had access to a much broader array of health professionals to deliver health care services, such as doctors, physiotherapists, dieticians, ergotherapists and others. Only seven "other health professionals" were identified as working in this area within the First Nation communities, compared to 22 in the non-Aboriginal sample.

In the Yukon, for the communities outside Whitehorse, there are virtually no services in the areas of career counselling, mental health, or counselling to deal with aging/geriatrics or disabilities. Only the larger communities of Whitehorse, Watson Lake and Dawson City offer respite services. Services for the deaf, such as sign language interpreters, are also non-existent. Transportation services for the disabled are only available in Whitehorse.

The same pattern regarding specialist and support services was found in all regions.

Training and Liability Issues

Appropriate accredited training for First Nation homemakers and personal care workers is almost non-existent in all regions. The Manitoba region is typical in that none of the homemakers working in First Nation home care programs has any formal training. However, in Manitoba's provincial program, personal and home care workers are trained through accredited programs at a provincial community college.

Furthermore, there is no evidence that Band health or social service workers who are determining client eligibility and allocating services have any training in client assessment or case planning and management.

The lack of appropriate training places the health and safety of First Nation clients at considerable risk. In the Ontario region, it was noted that homemakers have difficulty providing personal care services due to a lack of training. Homemakers in the Yukon region wanted more training in the area of personal care skills, such as the proper way to handle clients with mobility problems.

The lack of on-reserve home nursing services was found to be a critical issue which impacted on both the quality of services to First Nation clients and the liability of service providers.

At the present time, on-reserve patients requiring nursing services are forced to go to the nursing station, health clinic or a nearby hospital for treatment. This leads to discomfort for the patient as well as inadequate continuing care.

In First Nation communities with a community health nurse working in a public health capacity, this situation has greatly increased the liability risk to the nurse.

Part of this risk derives from the different roles and responsibilities of the community health nurse and the home care nurse. The community/public health nurse works in a community-based setting such as a health clinic, school or home. The focus of nursing activities is prevention and health promotion. Direct "hands on" care is minimal and is usually limited to immunizations and obtaining specimens for communicable disease-related care. The skill and knowledge requirements for the community health nurse are more oriented to health education, prevention of illness and the promotion of self-care, community development, empowerment, and communication.

The home care nurse primarily works in the home but is part of the assessment team that determines if the client can be maintained in or discharged to the home. The home care nurse also provides direct patient care, often using equipment and medical procedures found in hospitals. Recent advances in medical technology have increased the complexity of care that can be performed within the client's home and the need for specialized nursing skills. The nurse in this role must have access to ongoing training and resources to ensure safe, knowledgeable practice. The home care nurse also provides health maintenance activities that assist the client in maintaining independence. The role of the home care nurse in palliative care has also dramatically increased in the last few years, enabling clients to avoid or delay institutionalization.

Asking community health nurses to assume the responsibilities of a home care nurse places the health and safety of clients at risk, substantially increases the liability risk for the community health nurse and detracts from the community health role.

Directions for Continuing Care Programs

First Nation and Inuit societies have different traditions and approaches to health and healing that must be respected. Aboriginal healing is a way of life rather than a segregated or specialized activity. These traditions, which emphasize the multi-dimensional nature of people as physical, mental, emotional and spiritual beings, must be recognized in addressing the continuing care needs of First Nation peoples.

As Inuit and First Nations move toward self-government and jurisdiction over the development and delivery of health programs and services to improve the health status of their communities, the further development of health services, such as continuing care, which are managed and provided by First Nation organizations, is critical.

Based on the information gathered during the consultation process, meetings with First Nation organizations, communities and individuals as well as MSB field and regional staff, the following recommendations have been developed. It is recognized that these recommendations are only a beginning to meeting the full spectrum of home care needs.

1. Medical Services Branch, Health Canada, must secure a mandate and authorities for the provision of the home care nursing component of continuing care on-reserve, where it is not available.

2. Comprehensive/integrated community continuing care services must be established and include some or all of the following: assessment, single point entry, case co-ordinated management and management of service provision and evaluation. These steps will ensure that available funding for home care is used to maximum advantage. This would support a holistic/integrated approach involving all community services providing culturally appropriate support and care in First Nation and Inuit communities, where possible.

3. One federal department will have the authority and mandate for coordination of on-reserve continuing care in order address confusion over responsibilities/jurisdictions, a lack of program structure, fragmented service development, inconsistent standards and significant gaps in the availability of continuing care programs.

4. Regional and community diversity will be recognized through the development of case-managed funding options. This will ensure the implementation of equitable, co-ordinated and integrated continuing care services on-reserve. Ongoing funding, and sufficient flexibility to support managed and integrated coordination of continuing care with other community services, is required in order for the community to design and manage a system of service delivery which minimizes barriers to efficient and effective management.

5. Training, development programs and resources are required to ensure the availability of qualified health care providers to meet continuing care needs in First Nation and Inuit communities.

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